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Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Freedom of Information Act 2000 - Request Reference Fol/22/012
Motor Neurone Disease

Information Requested:

I would like to make a request under the Freedom of Information Act 2000 for the following information please:

- 1. How many individuals within your health board have been diagnosed with Motor Neurone Disease for the years 2017, 2018, 2019, 2020 and 2021? For the above, please share the above information into age categories for each year. *For example: 2017: 20 to 30 years - 6 individuals***

Cardiff and Vale University Health Board (the UHB) does not hold this information. Under our Section 16 obligation to provide advice and assistance, I can inform you that the UHB does not capture patient episodes by diagnosis.

- 2. For 2017, 2018, 2019, 2020 and 2021, how much money has your Health Board received to spend on Motor Neurone Disease specifically?**

The UHB does not hold this information. However under Section 16, I can inform you that our finance information does not specify the amount of money signposted to specific diseases, it is all captured under "neurology".

- 3. For 2017, 2018, 2019, 2020 and 2021, how much money has your Health Board spent on treatment for Motor Neurone Disease?**

Please see above

- 4. Please indicate what services your health service offers to people with Motor Neurone Disease. If this information is available in a public place, please direct me to there.**

The South Wales MND Care Network (the Network) provides an overarching service to patients with MND in ABUHB, C&VUHB, CTUHB, SBUHB and HDUHB and South Powys. The Network is funded jointly by the MND Association and the Health boards. This funding pays for Care coordination.

Across South Wales there are there are 11 specialist clinics, most monthly, that offer 3 monthly review and assessment to patients . These are Multi-disciplinary clinics. Patients are seen by the MDT team which consists of Consultant Neurologist. Consultant in Palliative Medicine, Care





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coordinator, Respiratory services, Occupational Therapy, Physiotherapy, Speech and language therapy and Dietitian. The multidisciplinary team are local professionals paid for by the local Health board.

Finances

In terms of finances the Network service (which covers care coordination) is run on a 4 yearly grant submission to the MND Association. For the years up until 2019 the Health boards paid approximately 4.5% each towards the costs of the Network (as all other health boards involved). Since Dec 2019 this has increased to 9% each (£17,300 per year). The MND Association is currently paying around 50% of the cost of the total Network.

Year	Money Received from MND Association (£)	All UHB's Contribution (£)	Individual UHB contribution (£) i.e. SBUHB	Money spent (£)
2017	124.094	15.094	3018	139.949
2018	112.438	30.943	6118	143.381
2019	99.326	47.594	95188	146.900
2020	95.286	88.181	16.436 + 6000*	183.467
2021	91.164	98.561	18.512 + 6000*	189.725

(*Powys UHB)

Care co-ordination is just one part of the financial picture. MND is a complex and challenging condition and many professionals are involved in the care of a person with MND. The health boards also fund in addition:

- members of the multidisciplinary (MDT) teams (who also work with other conditions)
- Home visits and assessments for patients by members of the MDT.
- Equipment to aid mobility, breathing and feeding.
- Costs of hospital admission for planned procedures such as feeding tube insertion, but also emergency admissions for example, respiratory infections.
- Provision of non-invasive ventilation (where required) and on-going management.
- Continued Health care funding for care, either at home, in nursing home placement.

(This is not an exhaustive list)

It is impossible to calculate the cost of this care for any one patient or any one Health Board as needs will vary. The MND Association may have more information regarding costs of care





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generally. It is also impossible to give a figure for the amount a health board contributes to MND care similarly for the above reason.

Information about services can be found on the MND Association website

<https://www.mndassociation.org/support-and-information/our-services/care-centres/>

