

Dear

## **ATISN 22076 – Palliative and end of life care for children and young people in Wales**

Thank you for your request to the Welsh Government for information under the Freedom of Information Act (2000) received on 05 November 2024. You referred to the new service specification for palliative care, which is aligning with the national quality standards for palliative and end of life care for children and young people in Wales. You have specifically asked the following:

- 1. Please provide the latest draft of the service specification?*
- 2. Does the service specification state that infants, children and young people with life-limiting conditions, along with their parents or carers are to be involved in the development of advance care plans? (Yes/No).*
- 3. Does the service specification state that infants, children and young people with a life-limiting condition are to have a [named medical specialist](#) who leads and coordinates their care? (Yes/No).*
- 4. Does the service specification state that infants, children and young people with a life-limiting condition, their parents or carers and their siblings are to be given information about emotional and psychological support, including how to access it? (Yes/No).*
- 5. Does the service specification state that infants, children and young people with a life-limiting condition are to be cared for by a multidisciplinary team that includes members of the [specialist paediatric palliative care team](#)? (Yes/No).*
- 6. Does the service specification state that siblings and parents or carers of infants, children and young people approaching the end of life are to be offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No).*
- 7. Does the service specification state that infants, children and young people approaching the end of life and being cared for at home are to have [24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care](#)? (Yes/No).*
- 8. Does the service specification state that infants, children and young people with a life-limiting condition and their families are to have access regular short breaks for respite? (Yes/No).*

### **Response**

We can confirm that Welsh Government does not hold a copy of the draft service specification that you have requested and therefore unable to provide further details. The service specification is being taken forward by the national programme board for palliative and end of life care in the NHS Executive. You may wish to contact them directly using the following link: [foi.phw@wales.nhs.uk](mailto:foi.phw@wales.nhs.uk)

### **Next Steps**

The request you sent me contains personal information about you - for example, your name and address. The Welsh Government will be the data processor for this information and, in

accordance with the General Data Protection Regulation, it will be processed in order to fulfil our public task and meet our legal obligations under the Act to provide you with a response.

We will only use this personal information to deal with your request and any matters which arise as a result of it. We will keep your personal information and all other information relating to your request for three years from the date on which your request is finally closed. Your personal information will then be disposed of securely.

Under data protection legislation, you have the right:

- to be informed of the personal data we hold about you and to access it
- to require us to rectify inaccuracies in that data
- to (in certain circumstances) object to or restrict processing
- for (in certain circumstances) your data to be 'erased'
- to (in certain circumstances) data portability
- to lodge a complaint with the Information Commissioner's Office (ICO) who is our independent regulator for data protection

For further information about the information which the Welsh Government holds and its use, or if you wish to exercise your rights under the GDPR, please see contact details below:

Data Protection Officer  
Welsh Government  
Cathays Park  
CARDIFF  
CF10 3NQ  
Email: [DataProtectionOfficer@gov.wales](mailto:DataProtectionOfficer@gov.wales)

If you are dissatisfied with the Welsh Government's handling of your request, you can ask for an internal review within 40 working days of the date of this response. Requests for an internal review should be addressed to the Welsh Government's Freedom of Information Officer at:  
Information Rights Unit,  
Welsh Government,  
Cathays Park,  
Cardiff,  
CF10 3NQ

or Email: [Freedom.ofinformation@gov.wales](mailto:Freedom.ofinformation@gov.wales)

Please remember to quote the ATISN reference number above.

You also have the right to complain to the Information Commissioner. The Information Commissioner can be contacted at:  
Information Commissioner's Office,  
Wycliffe House,  
Water Lane,  
Wilmslow,  
Cheshire,  
SK9 5AF.

However, please note that the Commissioner will not normally investigate a complaint until it has been through our own internal review process

Yours sincerely,