Oifig an Stiúrthóra Náisiúnta Cúnta
Oibríochtaí Meabhairshláinte

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Deputy Colm Burke,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.

23rd February 2024

PQ Number: 53563/23
PQ Question: To ask the Minister for Health what action his Department is taking to ensure that people living with epidermolysis bullosa have access to mental health services; and if he will make a statement on the matter. -Colm Burke

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Dear Deputy Burke,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for Health for response. I have examined the matter and the following outlines the position.

Epidermolysis Bullosa (EB) is a distressing and painful genetic condition causing skin layers and internal body linings to separate and blister at the slightest touch. It affects approximately 1 in 18,000 babies born, equating to approximately 300 people in Ireland, and can range from mild to severe. Severe forms can be fatal in infancy or lead to dramatically reduced life expectancy, due to a range of complications from the disease. Patients with severe EB need wound care and bandaging for several hours a day and the condition becomes increasingly debilitating and disfiguring over time. Adult patients with severe forms are extremely susceptible to an aggressive form of skin cancer. There is currently no treatment or cure for EB. In Ireland, children with EB are cared for at the multidisciplinary clinic in Children's Health Ireland, Crumlin and adult patients at a multi-disciplinary clinic in St. James's Hospital. Care requires the involvement of many different clinical specialists to extend life span and improve quality of life.

The National Rare Diseases Office has developed a series of integrated care pathways for rare conditions. These care pathways are based on clinical practice guidelines and developed in collaboration with national clinical experts and Irish patient organisations.

The development of care pathways is a priority for the health service. This is further outlined in the Irish healthcare policy for integrated care, Sláintecare and European rare disease policy as recommended by the European Reference Networks.

The care pathways aim to:

- empower those affected by rare conditions to navigate the health service
- increase knowledge and awareness of rare conditions
- improve patient outcomes (more timely diagnosis, reduce waiting times to access services)
- support delivery of integrated multi-disciplinary care
- enhance links between across acute, primary and community care services

- be educational and clinical support tools
- enhance clarity of roles and responsibilities

Included in the pathway Patient representatives emphasised the importance of a holistic approach to highly specialised care, with a key focus on access to psychosocial care. Rare disease pathways can signpost patients to therapeutic interventions, psychological care and social services, thereby supporting patients and families to navigate education, employment and welfare supports. across the wider RD patient community which prioritise improved social inclusion, mental health and quality of life as a means to redress the detrimental impact on personal, professional and socioeconomic status experienced by so many people living with a rare disease as Epidermolysis Bullosa.

There are no dedicated mental health supports for adults in Ireland diagnosed with epidermolysis bullosa.

Patients with epidermolysis bullosa can have mental health issues as any other person in the community. Patients with epidermolysis bullosa who present with moderate to severe mental health issues are referred to their local community mental health teams for assessment and treatment and will be managed mainly by General Adult Psychiatrists.

Further information on this can be found by contacting the following

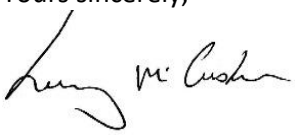
National Rare Disease Office
Mater Misericordiae University Hospital, Eccles St., Dublin 7.
Email: rare.diseases@mater.ie
Telephone: 01 854 5065 Hours: Monday to Thursday 9.30am to 1.30pm

More information on the care pathways project is available by clicking on the link below:

Designing Rare Disease Care Pathways 2022 (PDF, size 1.8 MB, 14 pages)

I trust this information is of assistance to you.

Yours sincerely,



Tony Mc Cusker
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