

# P-05-912 Supporting sudden and unexpected death in children and young adults

Y Pwyllgor Deisebau | 19 Tachwedd 2019  
Petitions Committee | 19 November 2019

Reference: RS19/10865-2

## Introduction

**Petition number:** [P-05-912](#)

**Petition title:** Supporting sudden and unexpected death in children and young adults

**Text of petition:** We call on the National Assembly for Wales to urge the Welsh Government to provide support for a service here in Wales to ensure families who unexpectedly lose their child or young adult aged 25 years and under get the support they require.

In February 2012 my son George died suddenly in an Emergency Unit in Wales. We walked out into the night with nothing, alone and frightened. Nobody came, nobody reached out to support us and it was left to devastated friends and family to support my husband Paul and I. Five days after we lost our son my surviving two young children and I faced more heartache when Paul took his own life. Once again nobody came.



Families require support immediately after such loss. They need to have a point of contact if they have questions and a friendly ear to listen. You never get over the loss of your child and families need to know there is long term support in place for to help them through the grieving process.

There is no planning or preparation prior to a sudden death and the effect of traumatic loss can have a huge impact on the mental health of parents, siblings and other family members. We believe this support is essential and will prevent families walking out into the night with no hope, no support and most importantly without their child.

### **Additional information**

Since 2012 I have been determined to ensure families get the same support when they say goodbye to their child as they do when they welcome it into the world at birth. 2 Wish Upon A Star was established to support families and staff through the unexpected loss of a child or young adult aged 25 years and under. This support includes memory boxes, counselling and an immediate support pathway working with health boards and police forces here in Wales. We have had more than 465 referrals since we started supporting families in 2015. The causes of death include SIDS, accidents, illness and more recently many young suicides. The feedback we get from both families and staff has been extremely positive, but we know many families are not being referred to us and many still need our support.

2 Wish Upon A Star already works with every health board in Wales and are supported by every police force. We have immediate support pathways in place in every Emergency Unit and Critical Care Unit and our pathway is clearly outlined in the Public Health Wales PRUDiC document. We also work with every Coroner, Mortuary, Organ Donation Team and Wales Air Ambulance to make sure no family is missed. However, many families still go without support. Staff have been known to 'forget' to give memory boxes, decided that the family of a 18 year old does not require support as 'he had stubble' and that the offer of support at time of death is 'not appropriate'. It is not for the professional involved to decide if a family require support.

We know by speaking to staff and families that our service is changing lives for everyone involved in the sudden death of a child or young adult and we want the Welsh Government to ensure all families get the offer of support when needed most.

## Background

The petitioner established the charity [2 Wish Upon a Star](#) to provide bereavement support for families who have suddenly and traumatically lost a child or young adult aged 25 years and under.

The Minister for Health and Social Services published a [statement on NHS children and young people bereavement services](#) in July 2019, setting out the latest developments in this area.

The Minister states that the Welsh Government expects health boards to provide appropriate bereavement support, working with charities where needed.

The Welsh Government has set up the Bereavement Support Working Group to help develop and deliver improved bereavement arrangements, and ensure health boards have suitable arrangements in place to help and support families who suffer the loss of a baby, child or young person.

The group comprises of policy leads in Welsh Government, representation from charitable organisations involved in supporting families who have suffered baby loss (including 2 Wish Upon a Star), service user representatives, members of the End of Life Care Board and clinicians.

The Welsh Government commissioned Cardiff University (through the End of Life Care Board) to undertake a scoping study to identify and gather information on structured bereavement services available in Wales. An [interim report](#) has been produced, and the final report was due to be published in October (but this does not appear to have happened yet). The [Minister's July statement](#) said that a meeting of the Bereavement Support Working Group was planned to discuss the findings from the report.

According to the interim report, one of the priorities of the End of Life Board in Wales 2017-2020 is for health boards to review the settings and capacities of their bereavement services with an aim that the needs of the bereaved are met. Further information can be found in the Welsh [Government's Palliative care and end of life delivery plan](#) (2017).

## Welsh Government response

The Minister for Health and Social Services states that 'ensuring appropriate support is in place for families that lose a child is a high priority' for him, and refers

to the written statement referenced above as an update on the work the Welsh Government is doing in this area. He goes on to say:

Health Boards are responsible for providing bereavement care and support for their population. The Welsh Government enhances Health Board bereavement provision by supporting a range of projects and initiatives.

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