

## **One page submission to Baroness Ilora Finlay regarding HSIB Draft Report on Palliative care**

### **Family's concerns:**

The HSIB draft report is flawed in the family's view in many ways:

1. **Scope** too narrow by far and the scope as defined Feb 2022 is not adequately or comprehensively addressed: <https://www.hsib.org.uk/investigations-and-reports/variatioins-in-the-delivery-of-palliative-care-services-to-adults-in-england/> So to look at inhibiting factors to good palliative care report it could also mention poor relationship with and input from GP, late referral for palliation, rapid decline with multiple metastases and mental trauma of suddenly changed prognosis after many months of thinking he was cured.
2. **Very inaccurately and incompletely** representing family experience and family concerns during Dermot's last few months of illness with many different health professionals involved. Family have given extensive feedback to chapters 2 and 3 of report. There is a misrepresentation of reality including to the Subject Matter Expert involved. The report gives more credence to the GP account than the family's, the latter of which was actually given after GP had been met by investigators and numerous times since then. HSIB have not adequately used the family story. The family's account was given after their close reading of medical notes.
3. **Poor GP** service which was core to the delayed initial diagnosis and also delayed metastatic diagnosis. This is part of story that cannot be ignored given the focus of the Investigation. In this kind of rural setting the GP has a vital role. Moreover the fact that GP is part of 'core palliative service' means how specialist services integrate with these core services has to be part of a service specification for any recommendations regarding palliative services. This is especially important now given ongoing pressures on GPs and challenges they have delivering continuity of care, itself a subject of another ongoing HSIB investigation.
4. **Late diagnosis** was also due to lack of scans and x rays advised by Marsden RMH after post-surgery re-grading. There were none between March 2020 and October 2020, when privately purchased. This is not in the scope of the investigation but its consequences, that is late diagnosis of extensive spread, are very relevant. There was no ongoing CNS support. RMH and Norfolk Norwich Univ. Hospitals had CNS nurses involved briefly but no one recognized by patient with an ongoing relationship to pick up symptoms of metastases, to get to know Dermot so help him psychologically with traumatic re diagnosis, or to handover to palliative services.
5. **Palliative services**, whilst undoubtedly challenged by a very ill, rapidly deteriorating, late diagnosed patient also did not carry out a 'holistic assessment' to understand the challenges, both psychological and physical Dermot had to face. The family has made an extensive submission on this, as widow says 'it was just a conversation not an assessment'. The service appeared to show no understanding of sarcoma (eccrine porocarcinoma prominent in the notes) nor why he should have longstanding symptoms e.g. were they confused by the severe nausea and severe anxiety, neither of which was responsive to simple intervention. The family asks whether local hospice availability would have meant earlier symptom control. Symptoms weren't controlled until just before he lost consciousness and died. The service only seemed to really know what to do when he was in last few hours of life.
6. **Covid was not a key factor**. There were delays in face to face assessments but this cannot account for a lack of timely, thorough physical examination between surgery follow up May 2020 and Hospital admission November 2020. The question remains whether Dermot would have had the same experience outside of Covid times.
7. **The Reports discussion of expectations around death** and service 'optimism' was very one sided. Dermot would have had a better chance of coming to terms with his terminal prognosis if both oncology and palliative services had been better able and/or willing to recognize what could happen and treat him with the urgency he deserved.
8. **How palliative care integrates with oncology services** is a big issue giving great therapeutic strides and service developments, yet there is a need for accompanying palliative back up and expertise when therapy does not work. The report does not mention this.
10. **Discussion on meeting of palliative needs and service expectations** were very weak and not patient centered.
11. The **whole investigation model** by excluding a true representation of the patient journey has reduced the ability of HSIB to come up with all key lessons from the patient story which are generalizable and would achieve the goals of maximum learning so that a patient like Dermot would be less likely to have a similar traumatic experience. **END.**