

## Regulation 28: REPORT TO PREVENT FUTURE DEATHS (1)

NOTE: This form is to be used **after** an inquest.

### REGULATION 28 REPORT TO PREVENT DEATHS

#### THIS REPORT IS BEING SENT TO:

- 1 Nottingham and Nottinghamshire Clinical Commissioning Group

#### 1 CORONER

I am Miss Laurinda Bower, HM Assistant Coroner, for the area of Nottingham City and Nottinghamshire

#### 2 CORONER'S LEGAL POWERS

I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.

#### 3 INVESTIGATION and INQUEST

On Twenty-Fifth March 2020 I commenced an investigation into the death of Owen Joseph HINDS, aged 26. The investigation concluded at the end of the inquest on 29 January 2021. The conclusion of the inquest was:

I a Systemic Inflammatory Response Syndrome

I b Bronchopneumonia

I c

II Cirrhosis & Non-Alcoholic Fatty Liver Disease,

Congestive Cardiac Failure, Obesity & Nutritional Impairment, Low Albumin, Autism

#### 4 CIRCUMSTANCES OF THE DEATH

Owen Joseph Hinds was a young man with Autism without Learning Disability (formerly known as Asperger's Syndrome).

His Autism led him to follow a restricted diet (which would likely now be diagnosed as ARFID - Avoidance Restrictive Food Intake Disorder).

His restricted diet led to chronic nutritional deficiency and obesity.

Professionals worked with Owen on psychological and behavioural strategies to improve his diet. There was limited sustained improvement, but it was felt that Owen retained capacity to decide what to eat and drink.

His physical health was monitored in primary care in accordance with his wishes, as he was felt to have capacity to consent to healthcare observations and frequently exercised his right to decline observations.

Sadly, Owen's lifestyle probably led to the development of chronic liver disease and a degree of heart failure. These conditions were not detected or diagnosed in life, despite monitoring, and probably contributed to his death from an overwhelming chest infection on 28 February 2020, at the Queen's Medical Centre, Nottingham.

Owen's Autism was the root cause of his tragic and untimely death because it prevented him from accessing the medical assistance that he required. There is no specialist service commissioned to provide ASD patients with long term dietetic support, and I heard this is what Owen needed

**5 CORONER'S CONCERNS**

The MATTERS OF CONCERNS are as follows:

- 1. There is no specialist service commissioned to provide ASD patients with long term dietetic support for ARFID symptoms, despite the increasingly prevalence of ARFID diagnosis.

At the time of the inquest, I was informed that Owen did not meet the criteria for support from any of the Dietetic services.

The Nottingham City Autism Service (NCAS) went above and beyond their remit in co-ordinating support from his GP. The service is commissioned to provide diagnostic and short term post-diagnostic intervention, yet they worked with Owen (as they do with many other patients) for years in order to bridge the gap in service provision. However, they could not provide the sustained ARFID support that Owen required.

Owen did not meet the criteria for support from the Eating Disorder Service or Dietetic Services (on account of his diet concerns being linked to his ASD) or Primary Care Learning Disability Nurse (as Owen did not have an intellectual impairment).

**6 ACTION SHOULD BE TAKEN**

In my opinion action should be taken to prevent future deaths and I believe you (and/or your organisation) have the power to take such action.

**7 YOUR RESPONSE**

You are under a duty to respond to this report within 56 days of the date of this report, namely by 02 July 2021. I, the coroner, may extend the period.

Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise you must explain why no action is proposed.

**8 COPIES and PUBLICATION**

I have sent a copy of my report to the Chief Coroner and to the following Interested Persons

.....  
I have also sent it to National Autistic Society

.....  
who may find it useful or of interest.

I am also under a duty to send the Chief Coroner a copy of your response.

The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it useful or of interest. You may make representations to me, the coroner, at the time of your response about the release or the publication of your response by the Chief Coroner.

**9**

**Miss Laurinda Bower**  
**HM Assistant Coroner for**  
**Nottingham City and Nottinghamshire**  
**Dated: 7 May 2021**