Parliamentary
and Health Service
Ombudsman

# Ignoring the alarms: How NHS eating disorder services are failing patients

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# Foreword

I am laying this report before Parliament under section 14(4)(b) of the *Health Service Commissioners Act 1993*.

First of all, I want to thank Dr Bill Kirkup for leading this complex investigation with expertise, insight and independence.

We received a complaint from Mr Hart in 2014 about the care and treatment of his daughter, Averil Hart, who had anorexia nervosa and died on 15 December 2012, aged only 19. This was a serious complaint involving several NHS organisations. We took too long to complete the investigation and I sincerely apologise to Mr Hart and his family for the delay.

Our investigation found that Averil's tragic death would have been avoided if the NHS had cared for her appropriately. Several NHS organisations missed opportunities to prevent the deterioration which led to her final admission to the hospital where she died.

We also found inadequate coordination and planning of Averil's care during a particularly vulnerable time in her life, when she was leaving home to go to university. There were also failures in her care and treatment in two acute trusts when she was seriously ill.

Sadly these failures, and her family's subsequent fight to get answers, are not unique. We have spoken to system leaders and experts in the field about the state of eating disorder services. What we have heard is reflected in the casework examples in this report.

In one case we investigated, a severely ill woman with suicidal thoughts was inappropriately discharged from hospital. Her care plan was inadequate and did not meet her care needs. As a result, nobody spotted the signs of deterioration in time and she died from a heart attack, triggered by starvation.

Another seriously ill woman with a history of vomiting and binge eating was referred to an Eating Disorder Service that was dangerously short-staffed. Again, there was no care plan in place and therapy sessions were inconsistent and unhelpful. Sadly, her condition deteriorated and she died of heart failure after taking an overdose, leaving a young child behind.

The families who brought their complaints to us have helped uncover serious issues that require national attention. Our report highlights five areas of focus to improve services:

1. The General Medical Council (GMC) should conduct a review of training for all junior doctors on eating disorders to improve understanding of these complex mental health conditions
2. Health Education England (HEE) should review how its current education and training can address the gaps in provision of eating disorder specialists. If necessary HEE should consider how the existing workforce can be further trained and used more innovatively to improve capacity. It should also look at how future workforce planning might support the increased provision of specialists in this field.
3. The Department of Health and NHS England should review the existing quality and availability of adult eating disorder services to achieve parity with child and adolescent services.
4. The National Institute for Clinical Excellence should consider including coordination in its new Quality Standard

for eating disorders to help bring about urgent improvements in this area.

5. Both NHS Improvement and NHS England have a leadership role to play in supporting local NHS providers and commissioners to conduct and learn from serious incident investigations. NHSE and NHSI should use the forthcoming Serious Incident Framework review to clarify their respective oversight roles in relation to serious incident investigations. They should also set out what their role would be in circumstances where local NHS organisations are failing to work together to establish what has happened and why, so that lessons can be learnt.

Averil Hart's case has important lessons for us too. We are currently in the process of developing our new three year strategy and the lessons from our handling of this case have informed some of my thinking in this area. In particular, I am determined to resolve complaints more quickly in the future so that important service improvements can happen without delay.

**Rob Behrens, CBE**
**Parliamentary and Health Service Ombudsman**

# Summary

Mr Nic Hart complained to us about the care and treatment provided for his 19 year old daughter, Averil, by four NHS organisations. He also complained about how those organisations, a local Clinical Commissioning Group and NHS England handled his complaint about what happened to Averil.

We found that all the NHS organisations involved in Averil's care and treatment between her discharge from hospital on 2 August 2012 and her tragic death five months later on 15 December failed her in some way. We found her deterioration and death were avoidable.

We found that most of the NHS organisations which dealt with Mr Hart's complaint failed to respond to his concerns in a sensitive, transparent and helpful way. Their investigations were not sufficiently thorough or joined-up. They did not provide Mr Hart with the answers he sought about Averil's care and treatment. These failings led Mr Hart to feel profound frustration with the NHS organisations and exacerbated his and his family's deep distress resulting from Averil's avoidable death.

Sadly we can do nothing to remedy the injustice to Averil. We have however made recommendations to remedy the injustice to her family and to ensure each of the organisations and the wider NHS learn from the mistakes made in this case. We hope that our recommendations will mean that no other family experiences what Averil and her family experienced.

# Wider recommendations

In addition to the recommendations to remedy the injustice Averil's family suffered, we also consider there are wider lessons for the NHS from her case and the others set out in this report. To address these, we also make the following recommendations:

- The General Medical Council should conduct a review of training for all junior doctors on eating disorders, informed by research being conducted by the Faculty of Eating Disorders at the Royal College of Psychiatrists;
- The Department of Health and NHS England (NHSE) should review the existing quality and availability of adult eating disorder services to achieve parity with child and adolescent services;
- The National Institute for Clinical Excellence (NICE) should consider including coordination as an element of their new Quality Standard for eating disorders;
- Health Education England should review how its current education and training can address the gaps in provision of eating disorder specialists we have identified. If necessary it should consider how the existing workforce can be further trained and used more innovatively to improve capacity. Health Education England should also look at how future workforce planning might support the increased provision of specialists in this field;
- Both NHS Improvement (NHSI) and NHS England (NHSE) have a leadership role to play in supporting local NHS providers and CCGs to conduct and learn from serious incident investigations, including those that are complex and cross organisational boundaries. NHSE and NHSI should use the forthcoming Serious Incident Framework review to clarify their respective oversight roles in relation to serious incident investigations. They should also set out what their role would be in circumstances like the Hart's, where local bodies are failing to work together to establish what has happened and why, so that lessons can be learnt.

# What happened to Averil Hart

Aged 18, Averil was voluntarily admitted to the Eating Disorders Unit in Cambridge on 19 September 2011[1]. She had a three-year history of anorexia nervosa and a very low body mass index which meant there was a significant risk to her physical health. Over the following eleven months as an inpatient she slowly gained weight.

Averil was very keen to take up a place at university in Norwich and doctors decided she could be discharged on 2 August 2012. She was still underweight and was referred to outpatient eating disorder services in Norfolk (the Eating Disorder Service) for ongoing treatment. This was to begin when Averil started university with a consultant clinical psychologist from the eating disorder unit providing therapy in the interim.

Averil started her university course in September 2012. She was not allocated a care coordinator until October. She registered with the GP practice at the University of East Anglia Medical Centre (the practice). The GPs at the practice at the time were asked to monitor her medical condition weekly.

Between 19 October and 23 November, Averil had six sessions with her new care coordinator (a psychologist) for cognitive behavioural therapy and weight monitoring. She saw a GP on three occasions between 12 October and 8 November. At the last appointment a locum GP told her she did not need to come back for a month.

Mr Hart and Averil's sister visited Averil at university on 28 November. They were shocked by how much weight she appeared to have lost and made an emergency call to the Eating Disorders Unit in Cambridge. As a result, a medical review with Averil's care coordinator and a speciality doctor from the Eating Disorder Service was organised for 7 December.

On the morning of 7 December Averil was found collapsed in her university room. She was taken by ambulance to the emergency department at the Norwich Acute Trust where she was admitted for three days. On 11 December Averil was transferred to the Cambridge Acute Trust.

Overnight on 11-12 December Averil's blood sugar fell to very low levels. She did not receive appropriate treatment for this and she became unconscious. She had suffered brain damage due to the low blood sugar levels. Tragically Averil died in hospital on 15 December 2012, aged 19.

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[1] Addenbrooke's Hospital is part of Cambridge University Hospitals NHS Foundation Trust, but the Eating Disorder Unit there is part of Cambridgeshire & Peterborough NHS Foundation Trust.

# What we found

Averil Hart was a young woman with anorexia nervosa. She died on 15 December 2012, aged 19, following a series of failures that involved every NHS organisation that should have cared for her. Her death was avoidable. There were multiple opportunities between August and December 2012 to identify what was happening to Averil, to intervene to remedy the situation at that time, and therefore to prevent the subsequent course of events that led to the final emergency admission to hospital which culminated in her death. All of these opportunities were missed.

Averil's illness had been serious enough that she was treated as an inpatient for over ten months from September 2011 in the Eating Disorders Unit in Cambridge, part of Cambridgeshire and Peterborough Foundation Trust (the Cambridgeshire and Peterborough Trust) but situated on the Addenbrooke's Hospital site. In April 2012, while still an inpatient, she received an offer from the University of East Anglia to attend university in Norwich, and was keen to take up the place that September. This would require her discharge from hospital, which is in any case a vulnerable time for those with anorexia nervosa, and it was clear that Averil's illness was severe. Averil would need to move to a new location, a new environment at university and a new clinical service, the Norfolk Community Eating Disorder Service (NCEDS); all of these would potentially further increase the risk of relapse subsequent to discharge.

Averil was assessed as fit for discharge, although it was recognised that she was vulnerable to subsequent relapse, and left hospital on 2 August 2012. At her request, responsibility for her care was transferred to NCEDS from her move to Norwich on 23 September 2012, and she was not seen by the Suffolk service that covered her home area. NCEDS was managed by the Cambridgeshire and Peterborough Trust and had been explicitly set up to improve services in the aftermath of a previous death. Given that Cambridgeshire and Peterborough Trust knew the risks of leaving hospital for a new environment and the risk of relapse, it was particularly important that there was explicit documentation of warning signs of deterioration in her condition and the contingency plan to be invoked if they materialised. But the care plan at discharge failed to set these out robustly or explicitly enough.

Following discharge, joint working between the Eating Disorder Unit and NCEDS was poor, and NCEDS was operating with staffing shortages due to recruitment difficulties. Neither Averil's weight nor her mental health was adequately monitored prior to her move to Norwich. Interim support was provided by the Cambridgeshire and Peterborough Trust, but there were gaps in weight monitoring from the outset. When she did move, there was a delay in allocating a care coordinator by NCEDS which meant that she was not supported or properly assessed for a further month, during which her condition deteriorated and her weight decreased significantly again. When she was first weighed in Norwich, she had lost 6kg, a very significant reduction for someone in Averil's condition.

These failures – of assessment, of coordination and of care planning and implementation at a time of heightened vulnerability – all represent missed opportunities to recognise that Averil's condition was deteriorating and that she was at significant risk, and missed opportunities to intervene to prevent the further deterioration that led to the final admission to hospital which ended with her death.

The care coordinator that was then appointed by NCEDS had no experience of looking after people with anorexia nervosa. While it is clear that much NHS care is properly carried out by newly qualified clinicians who are still gaining experience, it is a matter of significant concern that eating disorder services across the country are sometimes obliged to give lead responsibility for managing such a complex and challenging condition over an extended period to an inexperienced clinician. We are advised that this practice does sometimes happen in eating disorders services, because of the difficulty of recruiting and maintaining staff with the requisite skills and experience. Although the appointment was not out of line with established practice in the specialty because of the difficulty of recruiting and retaining staff with the requisite skills and experience, we believe that this is not a satisfactory situation and requires national attention.

When there is no alternative to an inexperienced care coordinator, it is vital that they be properly supported both in this role and as the clinician in day to day contact with the patient. The support provided by the Cambridge and Peterborough Trust to this Eating Disorder Service clinician was inadequate. A multi-disciplinary team should have been arranged, to provide input from other clinical disciplines including psychiatry and to provide another clinician in contact with Averil. This is important in providing scrutiny and challenge that can detect the behaviours often used to hide weight loss by those with anorexia nervosa without jeopardising the therapeutic relationship between the patient and the clinician principally providing care. The failure to provide multi-disciplinary team support left the care coordinator as the sole point of contact with Averil, and impaired the ability to detect deterioration in her mental and physical condition.

The failure to provide for multi-disciplinary team care also meant that there was no opportunity to pick up an error by the care coordinator in calculating Averil's four-weekly rolling average weight, contributing to an over-optimistic assessment of her weight loss. When the care coordinator went on leave, by which time Averil had become more unwell, no cover was arranged. The lack of handover to another identified clinician impaired the service's ability to detect the deterioration in her condition.

Averil was under the direct care of NCEDS from her arrival in Norwich on 23 September 2012, and her condition deteriorated markedly through to late November. The Cambridgeshire and Peterborough Foundation Trust was responsible for NCEDS; its actions fell far short of what should have happened and constituted service failure. The failure to ensure adequate surveillance that was capable of detecting the change in Averil's condition was another missed opportunity to prevent her further deterioration and the subsequent admission to hospital that culminated in her death.

Responsibility for monitoring Averil's physical health once she arrived in Norwich rested with the GPs of the University of East Anglia Medical Centre (the GP practice). The requirements had been clearly set out in a referral letter at the time of her discharge from hospital in August, but the GPs failed to follow them. Averil was not seen regularly, or as often as she should have been. When she was seen, many of the observations required were not made. Signs and symptoms of Averil's deteriorating health were missed. On 8 November, she was asked to return in a month's time, although monitoring was required weekly. There was no single point of oversight within the GP practice because Averil was not provided with a named GP.

Had the GPs done as they were asked, the deterioration in Averil's physical condition would have been recognised sooner and action taken before she reached the point of collapse. The GP practice's actions fell far short of what should have happened, and constituted service failure. Their failure to implement properly the straightforward monitoring that was required was another missed opportunity to intervene to prevent the subsequent deterioration that resulted in her final admission to hospital.

Averil's care was divided over this period, with the GP practice monitoring her physical condition while NCEDS took responsibility for mental health and the behavioural aspects of her eating disorder. We are advised that joint arrangements such as this are common in this field of clinical work. There may be reasons to separate care in this way, but it places a premium on effective communication and effective care coordination, particularly when the patient may be an unreliable source of information because of their condition. Communication is a two-way process that is the responsibility of both parties and not simply the transmission of a message, and in this case, it was not effectively established between the GP practice and NCEDS.

When Averil was seen by NCEDS in October, it was decided that responsibility for monitoring her weight would be taken on by them, with all of the rest of physical health monitoring continuing to be done by the GP practice. As two-way communication had not been established effectively, the GP practice concluded wrongly that, as care was now being undertaken elsewhere, they could reduce their already inadequate level of physical monitoring still further. The GP practice did not communicate their interpretation of the change of plan to NCEDS, who remained unaware of the error and unable to correct it.

This failure of communication between the two organisations meant that neither was effectively monitoring her condition, and was another missed opportunity to prevent the subsequent deterioration that resulted in her final admission to hospital.

As a direct result of the cumulative impact of this series of clear failures by the Cambridgeshire and Peterborough Trust, the GP practice and NCEDS, a very significant deterioration in Averil's condition went unrecognised. By the end of November she was very unwell and her weight had dropped to an alarming extent.

When Averil's father visited her on 28 November, he immediately recognised the marked deterioration in her condition over the preceding month. He sought to raise the alarm with her health carers. His initial approach was to the Eating Disorders Unit at Addenbrooke's Hospital, where she had been treated as an inpatient prior to her discharge four months previously. Averil's consultant during her admission declined to take the call although Mr Hart could hear her instructing that he be directed to NCEDS. A helpful and sympathetic response would have been to listen to his concerns, but she did not. Having then contacted NCEDS directly, Mr Hart was reassured to receive an email the following day telling him that action would be taken. He should not have been the first to recognise her condition, nor the first to prompt action.

Averil was due to attend NCEDS on Friday 7 December. Following her father's intervention, and recognising belatedly that there was significant concern about her deteriorating condition, NCEDS arranged for this planned visit to include a medical review. Averil telephoned NCEDS during the evening of 6 December and left a message cancelling her appointment. Her care coordinator at NCEDS attempted to telephone Averil the next day, but received no reply.

On the morning of 7 December, Averil was found in her room in a state of collapse. She was transferred by ambulance to the emergency department of the Norwich Acute Trust. On admission, she was acutely unwell, with a low temperature, low blood pressure and low blood glucose. She was also very underweight. All of this indicated clearly that her anorexia had deteriorated severely and now constituted a medical emergency that was potentially life threatening. It should have been clear that she was in urgent need of refeeding.

The urgency of addressing Averil's condition was not recognised by staff at the Norwich Acute Trust. Averil was allowed to walk around the ward (a common strategy to counteract feeding among people with anorexia that Averil was known to employ), and to feed herself from a trolley, so that her food intake was unknown. The medical team appeared focused more on pursuing other unlikely diagnoses than on the need to ensure an effective refeeding regime with support from mental health professionals. She saw no specialist eating disorders clinician for three days after admission, by which time her condition had deteriorated further. Nursing care was deficient and failed to monitor her condition effectively.

These clear failures of care wasted more time during which the continued further acute deterioration in Averil's condition remained undetected. The Norwich Acute Trust's actions fell far short of what should have happened and constituted service failure. This was another missed opportunity to intervene to prevent yet further deterioration in her condition, deterioration that culminated in her death.

When the seriousness of Averil's condition was finally recognised, she was transferred to a gastroenterology ward at Addenbrooke's Hospital, part of the Cambridge Acute Trust. She arrived at 2:40pm on 11 December, but was not seen by a doctor for almost five hours. Given her condition, this was a significant and inexplicable delay. Even when she was seen, the clinical assessment was cursory and no decision was recorded concerning her clinical risk or immediate care.

During the evening of 11 December, Averil's blood glucose fell further to a level that was clearly life-threatening. She was offered treatment, but refused. Inexplicably, there was no proper assessment of her mental capacity to take this decision, and no mental health assessment with a view to establishing treatment under the Mental Health Act.

A healthcare assistant had been provided by the Cambridgeshire and Peterborough Trust to sit with Averil at this time, to guard against any attempts by Averil to sabotage treatment, for example by excessive mobility. By now, however, she was too weak to be mobile and the role was redundant. Nevertheless, the healthcare assistant remained, but took no part in her basic care. We consider that she should have done more to assist Averil and her family.

Overnight, there were further clear signs that Averil was increasingly critically ill, including extremely low blood glucose levels. Following an unsatisfactory telephone call between a junior doctor and a consultant that failed to result in effective communication, no definitive action was taken and she was found unresponsive the following morning. It became clear that she had severe brain damage due to extremely low blood glucose and that further restorative treatment was futile. Averil died at 11pm on 15 December 2012, with her family by her side.

These were multiple serious departures from the standards of care expected that meant that the critical nature of Averil's condition was not recognised and treatment was not implemented promptly, as it could and should have been. The Cambridge Acute Trust's actions fell far short of what should have happened, and constituted service failure. This was the final failure that led immediately to Averil's death, but it was the last of a long series of missed opportunities to recognise her deteriorating condition and intervene to prevent the need for her final hospital admission as an acutely ill medical emergency.

Following Averil's death, as with any avoidable harm, the question naturally arises as to what happened and why, and how will it be prevented from recurring in future. Averil's family, with Mr Hart taking a lead, rightly sought answers from the organisations involved. As happens to too many in these circumstances, he found the process to be difficult, unnecessarily painful and ultimately frustrating.

This was clearly a very serious clinical incident that required a commensurate investigation by the NHS. This would properly have been provided by an independent investigation, commissioned by all of the NHS organisations involved, which looked at the failures of care across all of the organisations and the failures of communication between them. In the event, the piecemeal investigations that were done comprised an unsatisfactory process that was unlikely to generate a complete account of what had gone wrong and how it could be remedied; nor was it likely to command the respect of the family that a thorough process had been undertaken.

The responses to Mr Hart's requests for information were delayed and appeared evasive, and information he requested was often not provided. The responses to his complaints were equally unsatisfactory, and often appeared defensive or protective of the organisation concerned. Some information stored in electronic format turned out to have been deleted; the decision to delete material related to a significant safety incident was ill-considered and inappropriate. An anonymised account of Averil's death was going to be used in the revised guidelines on management of severe anorexia nervosa (MARSIPAN) but was subsequently removed. Mr Hart and Averil's mother were given an account that inappropriate pressure had been brought to bear on the author to withdraw the account, but the author denied this and we were unable to substantiate it.

There were clear failings in the response to Mr Hart. The Cambridgeshire and Peterborough Trust's handling of Mr Hart's complaint was so poor that it was maladministration. The GP practice's investigation of Mr Hart's complaint was deficient and did not uncover the serious failings in her care. Their complaint handling was so poor that it was maladministration. The Norwich Acute Trust's initial investigation of Mr Hart's complaint was deficient and did not uncover the serious failings in her care. Their complaint handling was so poor that it was maladministration. The Cambridge Acute Trust's investigation of Mr Hart's complaint was deficient. It did not uncover the serious failings in her care or that her death should have been avoided. The Trust did not respond appropriately or sensitively to Mr Hart's follow-up complaints and their complaint handling was so poor that it was maladministration.

Individually, these failures are seriously unsatisfactory. Taken collectively, they paint a consistent picture of unhelpfulness, lack of transparency, individual defensiveness and organisational self-protection that is of great concern. It is hardly surprising that this leads to a lack of trust from complainants, in this case Mr Hart. Equally unacceptable are the missed opportunities to learn and to improve services inherent in the incomplete and defensive investigations of safety incidents such as this.

When Mr Hart's complaint reached NHS England, there was an opportunity for them to intervene to identify the inadequate and defensive nature of the previous investigations and complaint handling, and initiate an effective response. NHS England's actions, however, were inadequate. They failed to demonstrate that they understood the very serious issues Mr Hart complained about and, due to a misunderstanding, they closed his complaint without investigating it. NHS England's approach was not customer focused. It was so poor that it was maladministration.

The death of Averil Hart was an avoidable tragedy. Every NHS organisation involved in her care missed significant opportunities to prevent the tragedy unfolding at every stage of her illness from August 2012 to her death on 15 December 2012. The subsequent responses to Averil's family were inadequate and served only to compound their distress. The NHS must learn from these events, for the sake of future patients.

# Case summary – Miss B

Miss B had a history of binge eating and induced vomiting from the age of 13 but had not sought help in the past. When she was in her mid-twenties she went to her GP, worried about the effect her condition was having on her six year old son.

In the autumn of 2012 Miss B was referred by her GP to an Eating Disorder Service where she was assessed by a specialist nurse. Although Miss B continued to see the nurse, she was unhappy with the therapy she was receiving; her therapy sessions were frequently cancelled or her therapist did not show up. Nor was there any liaison between the nurse and Miss B's GP.

In the spring of 2013, the Trust responsible for the Eating Disorder Service contacted Miss B to invite her for a review of her care plan. Miss B declined, saying she did not think she had a care plan. She said the therapy had been inconsistent and had done 'way more harm than good'. She felt she had been 'dropped' and was now struggling with her eating disorder. The Trust repeated its invitation but Miss B did not respond. Her mental health then deteriorated significantly.

A month later the Trust discharged Miss B back to the care of her GP with no information about her condition, what had happened while she had been in their care, no information about her risk status or what further monitoring she needed. Following the breakdown of her therapy, Miss B was unable to keep down food and she became depressed and emotionally volatile.

Two weeks later Miss B took a large overdose of prescription medication. She called a friend and was admitted to hospital but died the next day of heart failure.

As a result of our investigation, we concluded that the funding the Eating Disorder Service received was woefully inadequate. Miss B's care was provided solely by the specialist nurse with no input from a psychiatrist or other professionals, despite this being contrary to good practice guidelines produced by the Royal College of Psychiatrists.

The actions and inaction of those involved in Miss B's care meant that she found herself in a situation where she was at high risk but not receiving any support or monitoring, either from her GP or anywhere else. In fact, the service Miss B received from the Trust fell so far short of good practice that it would have been safer had she not received any service at all.

The specialist nurse failed to properly assess Miss B's needs or the risks to her. Miss B's therapy was not consistent and the nurse was working beyond her competence, without the support of line management or professional supervision, and in breach of some of the basic standards of nursing practice.

Opportunities were missed to provide Miss B with treatment that may have meant she would have lived. Her young son lost his mother. Both he, and Miss B's own mother have to live with the distress of her loss, and not knowing whether she would have lived if she had received an adequate service.

# Case summary – Miss E

Miss E was in her late twenties and had suffered from anorexia nervosa, with binge eating and vomiting, since adolescence. In early summer 2010 Miss E's weight and body mass index dropped and she became depressed and withdrawn. She was admitted for a short time to both a medical and a psychiatric ward. During this time, Miss E's mental capacity was assessed by a psychiatrist and she was considered able to make her own decisions about her medical care and treatment. This assessment was fundamentally flawed. Miss E lacked the capacity to make these decisions yet the psychiatrist and other staff failed to recognise this.

Nor did Miss E receive sufficient support given the major psychiatric symptoms she had, and there was a lack of knowledge and experience of eating disorders among staff supporting her at the hospital. She should have been referred to a specialist eating disorders unit as an urgent case.

Miss E was discharged home with a care plan that included checks by her GP, support from a home support service, a care coordinator and a clinical psychologist. Once back at home Miss E started to regularly make herself sick and cancelled her home support service. Her condition deteriorated and she died soon after from a heart attack.

Miss E's discharge from hospital was poorly planned and her care plan was inadequate for her needs and not in accordance with guidance. Given her severe illness and suicidal thoughts, Miss E's care plan should have included close supervision and frequent mental and physical assessments. None of this was done.

Her induced vomiting at home reduced her blood potassium to dangerously low levels that triggered the heart attack. In hospital, doctors would have regularly checked this and treated her. If Miss E had been in hospital, it is likely she would have survived.

# Our wider observations and recommendations

Sadly, the failures in Averil's care and treatment, and her family's subsequent experience of fighting to get answers about what had happened are not unique. We have seen in our casework, and in our discussions with system leaders and experts, the same problems of poor transitions and coordination and a lack of awareness replicated. All of which contribute to an area of care that is at risk of failing its patients. In the words of one eating disorder specialist we spoke to: *'it is a miracle we don't have more tragedies'.*

**Awareness**

Eating disorders affect over 725,000 people in the UK.[2] Yet training for most doctors on this complex and serious mental illness is limited to just a few hours amongst many years of training. Our experience of investigating Averil's death shows this is not enough. GPs, often the first port of call for people with eating disorders who seek help, should be equipped with enough knowledge of the illness to know what steps to take next, including when and where to refer a patient to another service. Medical professionals in acute settings also need to understand the nature of anorexia nervosa and the behaviours that sufferers may display. As a result of the failure of staff at the Norwich Acute Trust to recognise that Averil needed urgent attention when she was admitted, she was allowed to walk around the ward and her food intake was unknown; common 'sabotaging' behaviours that people with anorexia nervosa can use. Likewise, understanding whether a patient has the mental capacity to make a decision to refuse treatment is critical in cases like those highlighted in this report.

The failure of staff in both Averil's and Miss E's case to recognise the nature of their illness and seek appropriate advice about treatment could have been easily remedied with some additional training and awareness of the relevant guidance.[3]

**Recommendation**

*The General Medical Council (GMC) should conduct a review of training for all junior doctors on eating disorders.*

The Faculty of Eating Disorders at the Royal College of Psychiatrists is currently conducting a survey of medical schools and colleges to better understand the paucity of training on eating disorders. We would encourage the GMC to use the findings of this research to inform their review.

**Transition**

As Averil's case shows, moving between services is a particularly challenging time for people with eating disorders. These transitions between services in different geographical locations, or from child and adolescent eating disorder services to adult ones, are recognised as high-risk, with students moving to university being identified as particularly vulnerable.[4]

Child and adolescent eating disorder services have received specific focus in recent years with increased Government funding to drive improvements and guidance on establishing and maintaining community eating disorder services for children and young people.

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[2] https://www.b-eat.co.uk/about-eating-disorders/types-of-eating-disorder

[3] NICE guidelines and MARSIPAN guide

[4] Eating Disorders: recognition and treatment; draft NICE guidelines; December 2016

However, for good quality transitions to be the norm, there needs to be dual focus on the quality and availability of adult eating disorder services, particularly given how frequently these conditions continue into adulthood. There also needs to be greater availability of good quality adult eating disorder services, which are currently subject to significant geographical variation meaning access to specialist support can be hugely divergent. Without these changes, adult eating disorder services will remain a Cinderella service and the experiences of the people in this report will be replicated, with similarly tragic consequences.

**Recommendation**
*The Department of Health and NHS England should review the existing quality and availability of adult eating disorder services to achieve parity with child and adolescent services.*

In addition to CQUINs[5] and new NICE guidance on eating disorders, NHS England and the Department of Health should consider the possibility of developing benchmarking guidance for adult eating disorder services and appropriate measures of success for this. Any guidance should take account of any funding earmarked within the Five Year Forward View for Mental Health for adult eating disorder services and the availability of resources locally so that standards are achievable.

**Coordination**
NICE's guidance on eating disorders specifically identifies that particular care should be taken to ensure services are well coordinated when more than one service is involved, yet there are wide variations in how eating disorder care is coordinated. As all the cases in this report show, poor coordination is a starkly common issue. A detailed care plan that all providers involved in a patient's care pathway understand, and that comprehensively assesses an individual's needs and considers risks is an essential part of ensuring care is properly managed. Without this, and in the absence of frequent and clear communication between providers and the engagement of appropriate multidisciplinary expertise, there can be tragic consequences.

Another challenge in achieving good coordination of care for people with eating disorders is the scarcity of specialists who can provide the type of care people like Averil need. This often means one or two professionals have responsibility for patients with eating disorders across a large geographical area, or that people are unable to access support where they live. In Averil's case, this meant that the only person available to act as her care coordinator was someone with no experience of looking after people with anorexia nervosa. In Miss B's case, the Eating Disorder Service had not been properly commissioned meaning that staffing levels were too low and clinical supervision and multidisciplinary input was not available. These situations cause us significant concern.

**Recommendations**
*NICE should consider including coordination as an element of their new Quality Standard for Eating Disorders.*

*Health Education England should review how its current education and training can address the gaps in provision of eating disorder specialists we have identified. If necessary it should consider how the existing workforce can be further trained and used more innovatively to improve capacity. Health Education England should also look at how future workforce planning might support the increased provision of specialists in this field.*

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[5] Commissioning for Quality and Innovation payments framework

**Investigations and learning**

Before bringing his case to us, Mr Hart had been in correspondence with six different organisations over the course of more than a year and a half. None of those organisations had worked together to conduct either a coordinated investigation into why Averil died, or to provide a coordinated response to the family. This is something we see time and again in the cases we investigate; rather than organisations working together to understand what happened and why, and to learn and improve, the burden instead falls to families. This process serves to exhaust all parties and undermines peoples' trust that the NHS is capable of preventing others from suffering the same experiences.

Commissioners are key to ensuring effective coordination takes place when care spans multiple organisations but system leaders also have a crucial role to play in providing the necessary oversight so that these complex investigations can be carried out successfully.

We welcome the programme of work being rolled out by the Department of Health in response to the Care Quality Commission's Learning, Candour and Accountability: A Review of the way NHS Trusts review and investigate deaths of patients in England. We also look forward to seeing the contribution that the Healthcare Safety Investigation Branch (HSIB) makes to driving up standards in local investigations. However, these developments should not be seen as a panacea. In all these new initiatives and approaches, system leaders including NHS England and NHS Improvement must make sure provider organisations are supported to respond in a coordinated, open and transparent way when things go wrong.

Specific focus by HSIB and Health Education England in developing standards on approaches to conducting multi-organisational investigations and the development of single investigation reports drawing together collective lessons across care pathways would help greatly here.

**Recommendation**

*Both NHS Improvement and NHS England have a leadership role to play in supporting local NHS providers and CCGs to conduct and learn from serious incident investigations, including those that are complex and cross organisational boundaries. NHSE and NHSI should use the forthcoming Serious Incident Framework review to clarify their respective oversight roles in relation to serious incident investigations. They should also set out what their role would be in circumstances like the Hart's, where local bodies are failing to work together to establish what has happened and why, so that lessons can be learnt.*

# Our statutory role and how we considered this complaint

We make final decisions on complaints that have not been resolved by the NHS in England and UK government departments and some UK public organisations. We do this independently and impartially.  We are not part of government, the NHS in England or a regulator. We are neither a consumer champion nor arbitrator.

We are accountable to Parliament and our work is scrutinised by the Public Administration and Constitutional Affairs Committee.

We look into complaints where an individual believes there has been injustice or hardship because an organisation has not acted properly or fairly, or has provided a poor service and not put things right. We normally expect people to complain to the organisation first so it has a chance to put things right. If an individual believes there is still a dispute about the complaint after an organisation has responded, they can ask us to look into the complaint.

When considering a complaint we begin by comparing what happened with what should have happened. We consider the general principles of good administration that we think all organisations should follow. We also consider the relevant law and policies that the organisation should have followed at the time.

If the organisation's actions, or lack of them, were not in line with what they should have been doing, we decide whether that was serious enough to be maladministration or service failure. If we find that service failure or maladministration has resulted in an injustice, we will uphold the complaint. However, if we do not find that the injustice claimed has arisen from the service failure or maladministration we identified, we will only partly uphold the complaint. Alternatively, if we do not find service failure or maladministration then we will not uphold the complaint.

If we find an injustice that has not been put right, we will recommend action. Our recommendations might include asking the organisation to apologise, or to pay for any financial loss, inconvenience or worry caused. We might also recommend that the organisation takes action to stop the same mistakes happening again.

We investigated Mr Hart's complaint by listening carefully to what he told us about what happened to Averil and about his experience of how his complaint was handled. We considered the evidence he provided to inform our investigation.  We studied Averil's clinical records and interviewed key staff responsible for her care.  We also considered statements made by some of those staff.  We looked at evidence about the way each of the organisations handled Mr Hart's complaint.

We established what should have happened by referring to relevant standards and guidance. Key ones are listed in the annex. We also took advice from clinical advisers.

Our investigation was conducted by a team of investigators including Dr Bill Kirkup – Lead Associate Investigator.

# Annex

## Key standards and guidance

The Ombudsman's Principles: the *Principles of Good Administration*; *Principles of Good Complaint Handling*; and *Principles for Remedy*.

MARSIPAN guidelines
*MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa CR162* (Royal College of Psychiatrists and Royal College of Physicians), 2010.

National Institute for Health and Care Excellence (NICE) guidance

*NICE guidance 9: Eating disorders: Core interventions in the treatment and management of anorexia nervosa bulimia nervosa and related eating disorders*, 2004.

Department of Health
*The Care Programme Approach: Policy and Practice*, 2008.

National Institute for Health and Care Excellence (NICE) guidance
*NICE guidance 50: Acutely ill patients in hospital: Recognition of and response to acute illness in adults in hospital*, 2007.

Mental Capacity Act, 2005.
*The Healthcare Professions Council's standards for conduct, performance and ethics*, 2008.

*The British Psychological Society's generic professional practice guidelines*, 2008.

The General Medical Council
*Good Medical Practice*

The Nursing and Midwifery Council
*The code of conduct*

The Cambridge and Peterborough Foundation
*NHS Trust's care planning policy*, 2012.

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