Complaint Concerning Care Received by Averil Hart

Background Information for the Parliamentary & Health Service Ombudsman

Monday 18th August 2014

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Document Elements

The different forms of evidence used in our submission are presented in the following formats:

Averil's Diary & Words	*Medical Records*	*Guidelines/Communications*

Where important notes have been made, or outstanding questions remain, these formats are used:

Important Notes	**Outstanding Question**

Our Submission

Complaint to the PHSO concerning:

1. Failure of four NHS organisations to provide appropriate and adequate care to Averil Hart in her first weeks of University, resulting in the death of a young, high risk and vulnerable patient suffering from a treatable illness: Anorexia Nervosa.
2. Failure of these four NHS organisations to respond appropriately and adequately to our complaints regarding the death of Averil Hart, aged 19.

Background and Chronology of Care

Background

Anorexia Nervosa: Profile of the Illness

Anorexia Nervosa is an Eating Disorder, affecting approximately 1% of all females,[1] and a lower proportion of males. It is cited as increasing in prevalence in recent years, and is discussed in relation to broader themes of "body image." However, it remains a dangerous psychological condition. All-cause mortality of Anorexia Nervosa sufferers was found to be 5.9%,[2] and estimates suggest that 20% die without treatment.

Several characteristics of the illness make appropriate treatment both difficult and important.

- It is a compulsive disorder, resulting in behaviours deliberately inconsistent with the goals of treatment. Many patients engage in weight falsification techniques, which prevent true physical progress from being accurately monitored; some will be deliberately dishonest in treatment sessions, while others will engage in excessive exercise to compensate for food eaten.
- It requires both careful physical monitoring as well as psychological attention. Its requirements are, therefore, more complicated than either purely mental or psychological conditions.

Within the NHS, treatment of Anorexia Nervosa and other eating disorders is made more difficult due to the demographics of sufferers. The condition is most prevalent among young women, and tends to be diagnosed between the ages of 16 and 20. However, the majority of sufferers will, at that point, move from their home area to University, often over a significant distance, meaning that transfers of care are more frequent. Moreover, services for Adults (AMHS) and Children and Adolescents (CAMHS) are generally separate, necessitating a transfer in care responsibilities. Finally, the process of treatment and recovery may necessitate multiple inpatient admissions, which require funding and organisation.

These two sets of factors mean that Anorexia Nervosa patients, and those within the UK in particular, require careful co-ordination of their care between several organisations, both at the same time and through transitions. Risk is elevated at the points outlined above, and care must be designed to manage the risks that they pose. Gaps in supervision and monitoring, however small, reduce perceptions of support and encourage destructive behaviours. It is against these standards, elevated by the structure of the NHS and the nature of the illness, that care provided must be judged.

The NHS Organisations in Averil's Case

Throughout Averil's treatment, four NHS organisations provided care directly. This section outlines their role and details relevant to Averil's case.

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[1] Crisp, A. H., Palmer, R. L., Kalucy, R. S. (1976) *How common is anorexia nervosa? A prevalence study.* 205 B J Psych (2) pp.549-554; Hoek, H. (2006) *Incidence, prevalence and mortality of anorexia nervosa and other eating disorders* 19 Current Opinion in Psychiatry 4, pp.389-394

[2] Sullivan (1995) *Mortality in Anorexia Nervosa.* 152 Am J Psychiatry pp.1073-1074

Cambridgeshire and Peterborough NHS Foundation Trust

Cambridgeshire and Peterborough NHS Foundation Trust provided two of the stages in Averil's care: her inpatient treatment at Addenbrooke's, and her outpatient treatment at NCEDS, in Norfolk.

In 2008, the death of Charlotte Robinson, a student from Norfolk suffering from anorexia, led to a review of eating disorder services in the county, which found them to be unsatisfactory. To remedy these deficiencies, Cambridge & Peterborough NHS Foundation Trust (CPFT) was commissioned to provide the Norfolk Community Eating Disorder Service (NCEDS) in order to improve the quality of care. The coroner's report which led to the change was strongly worded:

> *It is the intention of NHS Norfolk therefore to ensure that should, in the future, there be another incidence of fatality from an eating disorder that services were available and accessible to manage the eating disorder. It will not be acceptable for lack of services, or clinical expertise, to be contributing factors in any future inquest.*

There could not, after 2008, be a lack of services or clinical expertise that led to the death of a patient without significant questions being asked. Our experience suggests that this warning has not been heeded in the years since Charlotte's death. Even during meetings during Averil's inpatient treatment, reports of "near misses" were discussed openly with NCEDS staff.

CPFT must demonstrate that it has met this requirement in its provision of treatment for Averil, and that both current and future patients are safe from the same risks.

UEA Medical Centre

UEA Medical Centre, formally Dr Edmonds & Partners, is a GP Practice based at the University of East Anglia, providing primary care and General Practice services for the students there. Averil registered there on the 27th September 2012.

Norwich and Norfolk University Hospital

Norwich and Norfolk University Hospital provides Accident and Emergency admissions, with a range of specialist inpatient wards. Averil was rushed to NNUH by ambulance after her collapse.

Addenbrooke's Hospital

Addenbrooke's Hospital serves the Cambridge area, but also hosts the S3 specialist inpatient ward provided by CPFT. Its emergency wards are run by Cambridge University Hospitals NHS Foundation Trust. Averil was due to be transferred to S3 on her arrival, but was admitted to ward N2 (an emergency ward) in order to be monitored closely overnight.

Averil Miranda Hart

Averil was a wonderful daughter and sister; she was born at home with her family around her. She was the cheeky, lovable, fun girl at the front of family and school photos, always with a smile and a song. Averil was academically brilliant, she loved writing, literature and the world around her. She also had a black belt in karate and was extremely sociable and outgoing. She loved life and she loved her family and friends, who all supported her. It was her dream to go to University to study English literature.

Averil's Illness

While still at school, Averil completed a school project on Anorexia Nervosa. She noted some of the behaviours involved, identified with them, and began to emulate them. On moving to sixth form at a new school, some of the behaviours became stronger. Although she achieved excellent results, in the months following her last A-level exams, she finally succumbed to the full strength of Anorexia. She lost significant weight over the months leading up to her exams, and was referred to S3 ward at Addenbrooke's, weighing just 30.4kg. She was unable to take up her offer from Durham University, instead, remaining as an inpatient for the next eleven months.

Averil's Diaries

Averil's love of literature, of writing, and of creativity extended through every area of her life. Each day, she wrote a diary recording her activities, her thoughts, and her struggle with anorexia. She began while she was an inpatient at S3, and writing in her diary became an important part of her life on the ward. When she was discharged, she continued to write, producing nearly eight full volumes.

Throughout our dealings with the NHS, the accounts we have been given of Averil's care have been obscured by the medical records and the opaque responses received from the institutions who treated her. We needed some certainty of the way in which Averil was treated, written in confidence without any self-interested influence. It is through Averil's diaries that we have begun to ascertain what happened to her, and why her treatment failed her and all those close to her.

The process of reading them has been painful. Through the last few entries, her formerly fluid, easy to read handwriting reduces to a scrawl. As her body fights to keep going, her writing betrays her slowly reducing mental capacity, with grammatical errors and spelling mistakes she would not otherwise have tolerated. In one of the final entries, she simply writes *"I am going, and I am going fast."*

When she arrived at university, it is clear that she begins to struggle with her independence from the safe routine at S3 Ward. She asked herself *"Why aren't we having a late night snack?"* and discussed her worries about food and her illness:

> *Before I could handle a 390 cal sandwich and a nice pudding and now the thought of an apple scares me… I don't feel comfortable eating a normal amount – how quickly I have regressed.*

The "anorexic voice" talked about in her medical notes becomes visible at certain points, rejecting help and the attention of others:

> *I don't want an eating disorder but I don't want help. I need to deal with it and only I can. I hate being reminded that I have one.*
>
> *Why is everyone so in my face? I feel as if I want to shut people out of my business.*
>
> *I am scared about opening up and letting someone help me. I feel comfortable in this routine and I don't want to have to change it even though I need to.*

> *I had to lie in therapy which I know isn't great. I won't see her for two weeks but I can't back off. I have to power forward.*

However, the most profound insight from her months at University is her account of her treatment, and her anxiety about the weekly weigh-ins at NCEDS:

> 4th October 2012:
>
> *Feel scared about my weigh in...I know that I've gone down. I am scared of changing my 'safe' routine.*
>
> 5th October 2012:
>
> *I am surprised I didn't lose more weight – 42 kg. I know it is different scales and lots of layers and not peeing.*
>
> 19th October 2012:
>
> *My BMI has dropped to 14.4 I think she said and that's really not good news. That's me losing nearly 6 kg or almost a stone since leaving hospital.*
>
> 22nd November 2012:
>
> *I am worried about the session tomorrow. I hate having to go in there and lie so much. I'd like to realistically know how much I weigh but I am worried they will put me in hospital if I don't seem to be progressing and I don't want that.*

Finally, she describes her physical symptoms, which show the severity of her condition, even before her treatment at NCEDS began:

> 21st September 2012:
>
> *I don't think I am eating enough. I can feel it in my tired body, and I feel unable to change and I am scared. I feel safe in this routine.*
>
> 14th– 15th October 2012:
>
> *Swelling in my ankles… It is getting harder to walk upstairs, and oedema in my legs is getting worse.*
>
> 22nd - 24th October 2012:
>
> *Hard to climb the stairs… My chest really hurts and my ankles are so swollen.*

These extracts are crucial to our account of Averil's care, showing clear evidence of her attempts to falsify her weight. Averil's physical condition declined so severely during her first weeks at university that she found it difficult to walk up the stairs: it is inconceivable that a well-managed service would have permitted such signs to go unnoticed.

Chronology of Care

After significant weight loss, from 53kg to 34.1kg, Averil's GP referred her emergency case to the Halstead Community Team in early 2011. She attended counselling sessions with Cope, a charity based in Colchester, and was then referred to her GP again, following further weight loss. She was sent as an emergency inpatient to S3 Ward at Addenbrooke's.

S3 Ward, Addenbrooke's

Averil was admitted to S3 ward at 30.4kg. She had suffered a fall before her admission, and described feeling weak and unable to exercise. However, she was admitted as a voluntary inpatient. She expressed a clear desire to get better, and explained that Anorexia was a factor getting in the way of her life and her chances to go to University.

During the subsequent months, Averil gained weight and attended regular counselling sessions. While we do not currently have access to Averil's medical records from that time period, we are told that she made progress, but that this progress had slowed, and that several psychological risk factors were present even days before her discharge from the unit. Her weight increased to 45.2kg, short of her goal of 50-52kg, and well below the "healthy" range. It was noted in her file that she lost weight during her home visits, away from the supervision of the unit, and that she still found it difficult to experience "negative" emotions. She was not mentally ready for independent living, but two months remained before she started at university, which could have been used to provide further treatment.

Despite this, Averil was discharged from S3 on 2nd August 2013, following an appraisal by Jane Shapleske and a meeting with Averil's mother on the 31st July. A risk assessment was carried out, but made little reference to the context into which Averil was to be discharged. According to relevant guidelines, further consideration should have been given to the fact that Averil was being discharged from one service to another, and that she was moving from home and family life to complete independence at university, where she would lack day-to-day family support. These great changes put patients at risk, and the failure to account for them affected the suitability of the treatment supplied by the services to which she was discharged.

Transitional Care

Although a referral was made to NCEDS in Norfolk, a significant delay in the referral process created a time period of over two months where transitional care was essential. During this period of transition, Sarah Beglin, Averil's care coordinator, was to provide monitoring and support for her. She was moving from a closed environment – with daily support, encouragement and treatment – to one where her contact with practitioners was much more limited. During this time, there was a need for co-ordination of Averil's care from the separate services involved, and a proactive approach to her monitoring, taking GP weight measurements into account. The latter stages of transitional care consisted of telephone calls alone, with no record of discussions related to weight or other essential parameters, which should have been recorded by the GP and discussed by the care co-ordinator.

As a result of this ad hoc arrangement, no handover meeting took place, but transfer of responsibility was achieved by telephone conversations. This meant that the full picture of Averil's condition was not emphasised to those involved, and each party charged with her care in Norwich was unclear as to the role of the others.

NCEDS: Secondary Outpatient Care

Despite having been referred on the 30th of July, Averil's first appointment with her new care co-ordinator, Vikki Powell, took place on the 19th of October, due to "staff shortages operating at that time" (SI, p.9). By this point, Averil's weight had decreased significantly, from 41kg the previous week to 39.2kg, a BMI of just 14.4. Taking it upon herself to record Averil's weight, rather than having the

medically qualified GP take this measurement, she wrote a letter to UEA Medical Centre, telling them to stop making weight measurements. This led to a cessation of Averil's visits there. For a patient with "severe anorexia nervosa (BMI <15)" in the MARSIPAN guidelines (Robinson *et al*, 2010) and nearing "concern" under the King's College Guidelines (Treasure, 2009), her decision was totally inappropriate, and it appears no account was taken for the increase in risk to Averil with no physical checks occurring after this point.

There is significant evidence, both in Averil's diaries, and from the medical notes, that this first session encouraged future weight falsification techniques, which Averil used to obscure her lack of progress. We argue that Vikki Powell, being newly qualified and inexperienced with Anorexia Nervosa, lacked the clinical ability to recognise these behaviours. In one meeting, she noted that the food diary was insufficient to effectively increase Averil's weight, while noting an increase in weight in the same session. This alone should have been sufficient reason to raise questions. Moreover, she failed to notice physical changes that provided evidence of weight loss, which would have been obvious to someone with medical training, and which, by the end of November, were painfully obvious to Averil's family.

Even in the absence of falsification techniques, the lack of resources at NCEDS led to a gap in Averil's treatment, during which time Averil was at high risk of rapid weight loss, and during which alternative provision for physical monitoring should have been made.

- At her last session on the 23rd November, Averil's BMI was recorded as 14.0, but just five days later, Averil's father and sister noted that her appearance was indicative of a BMI of 11-12, a condition which Averil had reached before inpatient admission, with which the family were all too familiar.

We argue that, even in the absence of falsification techniques, the risk of such rapid weight loss should have been appreciated by NCEDS and VP. Averil's CPA Part II, issued to NCEDS and VP by Addenbrooke's on Averil's discharge, noted that Averil's weight loss "may be sudden" in a crisis situation, and that Averil would "begin to shut herself away". Moreover, in her CPFT weight records of inpatient treatment, a weekly loss of more than 3kg was recorded in 2011. By leaving Averil a fourteen day gap without any medical or psychological support, the risk of sudden weight loss, which should have been appreciated by NCEDS, increased dramatically.

Having visited Averil on the 28th November, her father was shocked by her appearance, and by her slurred words and slow responses. That evening, he phoned S3 ward and left a message with Carol Downe (one of Averil's nurses at S3) stating that Averil was in a "worse condition than when she had been admitted as an emergency patient in 2011", and calling for immediate action. Nurse Downe called back to both Mr Hart and Mrs Campbell, in two separate calls, on the 29th November, to say that NCEDS had been informed of Averil's deteriorating condition. It was understood that immediate and effective action would be undertaken. On the 30th, an e-mail was sent to request a medical review, and a review was eventually scheduled for the 7th December.

It was clear that this action was too little too late, and that no plans had been made for emergency scenarios. As noted in CPFT's Serious Incident Report, it is doubtful that any review would have taken place had it not been for this emergency call. The department's response to Averil's father's emergency call was chaotic. A flurry of e-mails showed no ability to deal with a patient whose life was at risk, with the medical doctor in the service structure – Dr Jaco Serfontein – based in Cambridge, over an hour away. The result of the call was that a clinical review was scheduled a week later, by which time Averil had been found unconscious, was hospitalised and near death. Only after three days at NNUH did the NCEDS team finally visit her.

UEA Medical Centre: Primary Outpatient Care

UEA Medical Centre were instructed to monitor Averil's physical health. On September 27th they received a telephone call from Sarah Beglin, explaining to them that Averil would be registering with them, but that she was "still regarded as fragile" and that a "new start at Uni could be [a] potentially

dangerous time for her." She was vulnerable, and Dr Beglin requested the "safety net" of the medical centre, and a named GP for Averil. The discharge summary also required them to carry out bi-monthly blood tests, and to check her pulse, weight, blood pressure and physical strength each week.

In the weeks that followed, Averil was not assigned a named GP, and was seen five times. On 29th September, her weight alone was recorded, while only on the 25th October did the doctor finally carry out all four tests required. Her last appointment was on the 8th November, where only a pulse was taken, and the note "review in a month" was added to her file. **We believe that this treatment was insufficient.**

- Despite clear initial instructions, following a subsequent letter amending them, they were not followed at all, and the importance of continued physical monitoring was largely ignored.
- Averil's discharge summary highlighted the risk that she may suddenly lose weight, and that several tests would be required on a regular basis, but no action was taken.
- The Centre's notes themselves also added an instruction to do blood tests the following week: this was never followed up.

Norwich and Norfolk Hospital

Averil was found by her cleaner on December 7th in a collapsed state, and required immediate admission to the Norwich and Norfolk Hospital. Here, she was admitted to the Gastroenterology ward with liver symptoms caused by paracetamol poisoning, and with low blood sugar caused by her anorexia. Averil eventually agreed to a glucose infusion, and her liver was treated. However, over the weekend, she was required to feed herself from a trolley on the ward, and was permitted to move without restrictions against MARSIPAN guidelines. This meant that she sustained a fall, suffering a head injury. In addition, it was clear that Averil's reported food intake was more than she was actually consuming. When visiting on the 11th December, the NCEDS team noted the need for 1:1 care, and her non-compliance with an existing treatment programme. They also established that she needed nasogastric feeding, but this was not provided. During this time, her condition continued to worsen, as noted by the consultant reviewer.

The Hart family could see that this treatment was insufficient to help Averil, and arranged for her to be transferred back to S3 at Addenbrooke's. This occurred on the 11th December 2012.

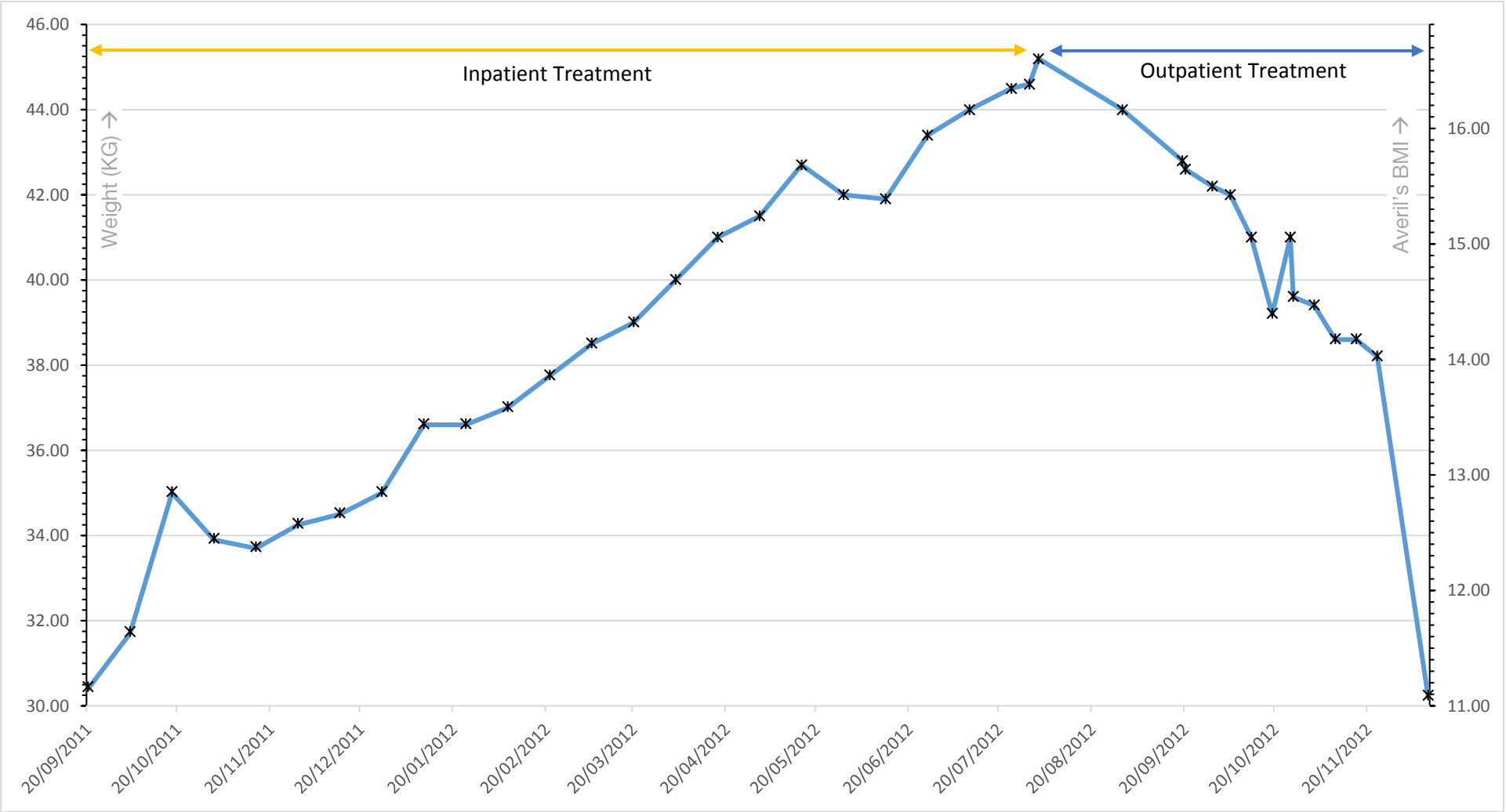
Addenbrooke's Hospital

Averil arrived at Addenbrooke's on 11th December 2012, where she was admitted to N2 ward after a six hour delay. Here, she was removed from her glucose drip, and blood tests were ordered. Instructions were left to monitor Averil's blood glucose level overnight. However, due to a lack of clarity, and due to Averil's refusal to accept further glucose, treatment could not be administered. No proper psychiatric assessment was made to determine her capacity to refuse treatment under the Mental Health Act 1983. Averil's blood sugar deteriorated overnight, and no action was taken to correct it. This was only noted the next morning, when Averil had slipped into a coma.

Discussions quickly turned to palliative care. She had been looked after by a bank nurse from a geriatric ward. We believe that Addenbrooke's failed to provide adequate staff to supervise Averil overnight, and the delay in admission meant that blood test results were not available to the consultant reviewing Averil's case. These failures contributed significantly to her death.

Graph: Averil's Weight and BMI during Treatment

Averil's BMI increased significantly throughout inpatient treatment, but even by October, at the first outpatient session, her weight had decreased dramatically, undoing much of the progress that she had made as an inpatient. Her loss of weight throughout outpatient care was continual and dramatic.



Summary of Complaints

Summary of Concerns Regarding Quality of Care (1-8)

Cambridgeshire and Peterborough NHS Foundation Trust

Averil's Discharge from S3 Ward	**Discharge from S3 Ward was too early:** Averil was discharged too early from S3, and evidence from her medical file suggests that her weight loss had not slowed, but suffered a setback. Her psychological progress was still incomplete, and further treatment may have been beneficial.
	Failure to undertake a full Risk Assessment: Averil's discharge documentation contained a risk assessment that was not complete. It did not comprehensively deal with increases in risk due to her transition to university, or staff issues at NCEDS.
	Failure to update and communicate Risk Assessment: Throughout Averil's care, commencing in S3, and afterwards, it is clear that risk was assessed differently at different stages, and no consensus was reached. Her risk level, and changes to it, were not effectively communicated between primary and secondary care teams, or to the family.
Transitional Care	**Failure to carry out a fully recorded handover meeting:** MARSIPAN guidelines require that a fully recorded handover meeting occurs on transition between services. Although Averil was not a MARSIPAN patient the requirement of a meeting would have prevented subsequent confusion as to the treatment to be provided.
	Failure to fill the "Care Gap" Between S3 and NCEDS: Averil's notes during transition suggest minimal contact with a psychologist, while being weighed at her GP, but there was a month without any weight measurement, and a month without any face-to-face contact with a psychologist. The gap in both physical and mental health care was not adequately filled by the transitional arrangement reached. This allowed Averil's serious condition to go without monitoring and untreated during an extremely vulnerable time for her.
Secondary Care at NCEDS	**Delays in commencing treatment:** While Averil was referred on the 30th July, and letters were sent expressing the urgency with which she needed to be "picked up", she was not seen until the 19th October, three weeks after she started at UEA.
	Appointment of an inexperienced "trainee" psychologist: Averil's psychologist, VP, was newly qualified, new to the NHS and new to treatment of patients with anorexia. She had no practical experience of acting as a patient's care co-ordinator, and appears to have started at the service just days before seeing Averil. This delegation was inappropriate.

Delegation of Care Co-ordinator Role to Inexperienced Candidate:

NCEDS appointed VP to be Averil's care co-ordinator, despite her lack of experience with NHS organisations and care co-ordination itself. It appears she failed to follow CPFT's policies in carrying out her function due to lack of knowledge of the role.

Decision of psychologist to undertake weight measurements:

Despite her lack of training to do so, VP undertook to weigh Averil on a weekly basis, and in so doing reduced the scope of UEA Medical Centre's monitoring, as appointments there then stopped, raising Averil's risk level.

Inaccurate BMI and Average Weight Recordings:

VP recorded Averil's weight, rather than BMI, despite the fact that guidelines are written in terms of BMI. She also failed to calculate a moving average correctly, resulting in a false sense of security about Averil's decline, resulting in increased risk to Averil.

Failure of VP to notice weight falsification and physical changes:

57% of outpatients engage in weight falsification, and Averil's diary shows that she routinely falsified her weight at NCEDS sessions. VP should have been trained to be aware of this risk and to take appropriate action to prevent it.

Averil also notes physical signs that are symptomatic of significant weight loss and deterioration of health, including oedema. VP lacked medical qualifications, yet concerned herself with physical monitoring. She was unable to notice these warning signs in Averil's appearance.

Failure of VP to account for typical Anorexia behaviours:

Averil's medical notes show that her weight did not increase or decrease along with her reported intake, and exercise was an issue. VP at no point accounted for anorexic tendencies of over-optimism and non-cooperation with treatment, taking Averil's statements at face value.

Failure of NCEDS to consider appropriateness of treatment:

Cognitive Behavioural Therapy (CBT) is known not to be effective under a BMI of 15, yet at all relevant times CBT was administered, Averil's recorded BMI was below this level. Neither VP nor her supervisors considered changing the course of treatment in the light of Averil's condition.

Failure of VP to follow procedures for absences:

VP organised leave at the end of November, but, having declared Averil a high risk patient, failed to follow NCEDS procedures for arranging holiday cover. She was aware of the risk of sudden weight loss, and Averil's already reduced BMI, yet did not act accordingly. This endangered Averil, and left her without supervision for the two weeks that led up to her collapse.

Failure of NCEDS to supervise their underqualified team member:

Neither VP's immediate supervisor nor those higher up in the hierarchy appears to have questioned VP's records of supervisions, or to have done more than check recorded weights and prompt on the development of care plans. No checks were made regarding VP's cover during absences. They failed to ensure that VP was competent, endangering both Averil and others.

	Failure to respond appropriately to an emergency call: When Averil's father telephoned S3 to warn of Averil's condition, he was asking for an emergency review. Typically, emergency reviews by RMOs or Team Leaders should be carried out within 24 hours. He was assured that action would be taken to protect her. However, it is clear that no plans existed to deal with this scenario, and the NCEDS team scheduled a review over a week after serious concerns were raised. The lack of procedure obstructed a timely medical review, which could have saved Averil.
	Failure to deal appropriately with an emergency patient: NCEDS discovered Averil's admission to hospital during Friday afternoon, but no team member attended until the following Monday. By this time, NNUH had delivered inappropriate treatment to Averil.
Primary Care at UEA Medical Centre	**Failure to provide a named GP:** In order to ensure continued physical monitoring, and the ability to observe changes in Averil's appearance, Dr Beglin requested a named GP. This was not provided, and Averil was seen by four separate staff members, making it harder to assess and compare both her mental and physical condition and to engage with her as part of an overall team caring for her.
	Failure to carry out tests as requested: Following Dr Beglin's telephone call, Averil's discharge summary letter was sent to the surgery, containing clear instructions to carry out four types of test. Of these, only weights were taken in her first appointments, and only once were all four tests carried out. No blood tests were ever ordered.
	Failure to follow King's College Guidelines: The King's College guidelines warn that BMI is an insufficient marker of progress, yet tests beyond weight were only carried out once at UEA MC, and the note "review in a month" was added to the file of a patient whose weight had decreased significantly while under their care.
	Failure to observe physical symptoms in counselling sessions: Averil's diaries reveal both weight falsification and physical symptoms of anorexia nervosa. None of Averil's appointments at UEA Medical Centre mentions either checking for these conditions, or reporting finding them, despite the evidence in Averil's diary that those conditions were present.
Norwich and Norfolk University Hospital	**Failure to provide appropriate specialist attention:** After Averil was admitted to NNUH, she was seen by a consultant gastro-enterologist, but no member of staff that saw Averil during her first three days was a psychiatrist, and no member of the psychiatric liaison team is recorded as having visited Averil (according to her records) until the visit of Dr Serfontein on Monday 11th December. There were, consequently, no anorexia nervosa-specific instructions on Averil's medical file, which may have protected her.
	Failure to provide care appropriate to Anorexia Nervosa: Averil was permitted to walk around the ward, meaning that she used up vital energy, and sustained a fall. She is also reported to have removed her N-acetyl cysteine drip at one point. She was also required to feed herself from a trolley on the ward, which resulted in a severe over-reporting of the foods that she had eaten, resulting in further weight loss.

Addenbrooke's Hospital	**Significant delays in admission to N2 ward:** Averil arrived at Addenbrooke's by 3pm on 12th December, but was not admitted until the late shift began at 8pm. Had she been assessed earlier, blood tests could have been taken which would have allowed face-to-face Consultant review and instruction. This resulted in blood tests being ordered too late, and being impossible to obtain in one instance. The advice received over the phone overnight about monitoring glucose was unclear, and, as a result, no glucose was administered and she became hypoglycaemic.
	Failure to make a Mental Health Act assessment: Despite Dr Serfontein establishing that Averil had no capacity at NNUH, on her admission to Addenbrooke's, neither an assessment of capacity to consent to treatment, nor consideration of detention under the Mental Health Act 1983 was made. As a result of this, Averil was able to refuse glucose after her levels plummeted overnight.
	Failure to appoint appropriate care staff to Averil's case: Averil was accompanied overnight by a Mental Healthcare Assistant, who raised no complaints or concerns. Despite the fact this "nurse" was sitting beside her, it was only when a doctor reviewed Averil on morning rounds that it was realised that she was barely breathing and unrousable. The failure of the MCA to notice her condition is evidence of her lack of qualification.
Inter-agency Communications	**Lack of communication between NCEDS and UEA Medical Centre:** NCEDS claims to work closely with UEA Medical Centre due to the high population of ED sufferers among the student body. However, in Averil's case, only one letter was sent from NCEDS to UEA Medical Centre, while no other forms of communication were made.
	Failure to verify results of medical assessments: NCEDS failed to check with UEA Medical Centre that appointments were scheduled, and that tests had been carried out.
	Lack of communication between NNUH and NCEDS: When Averil was admitted to NNUH, they failed to release information to the NCEDS team, despite their concerns and their role in treating Averil. This contributed to their failure to attend in a timely manner.
North Norfolk CCG	**Failure to check the quality of care administered by CPFT:** Despite paying CPFT approximately £850,000 each year, at a meeting with the Hart family on 17th May 2013, it was revealed by NNCCG that they do not engage in any form of proactive supervision or quality control of NCEDS' provision of services. Their view was that in the absence of a complaint, all must be well. This attitude is inappropriate and does not promote high quality services.

Summary of Concerns Regarding Complaints Handling (9-13)

North Norfolk CCG	**Lack of communication between NCEDS and UEA Medical Centre:** NCEDS claims to work closely with UEA Medical Centre due to the high population of ED sufferers among the student body. However, in Averil's case, only one letter was sent from NCEDS to UEA Medical Centre, while no other communications were made.
	Significant delays in responses to communications: Throughout our communications with NNCCG and CPFT, we received many responses after a significant delay. One response, to our official complaint about transitional care, took five months to arrive. It was written by Aidan Thomas, CPFT's Chief Executive. We have been generally dissatisfied with the time taken to respond to communications.
	Failure to adhere to promise of separate physician and psychiatric reviews of Averil's treatment: We were assured by Mark Taylor, Chief Executive of North Norfolk CCG (March 10th 2013) that an independent review would be carried out into the care provided to Averil, both by a physician and a psychiatrist. While Dr Vize's psychiatric opinion has been produced, we are yet to hear of any details about the physician's review.
	Failure to assure sufficient independence in the choice of reviewer: On the appointment of Dr Vize to produce a review of NCEDS' care, it became apparent that she had significant professional connections to Dr Shapleske and Dr Serfontein, and the family were concerned that this may not lead to a sufficiently impartial review. Dr Shapleske has an interest in a positive report, as her CPFT service is tendering for NCEDS in October 2014. No account was taken of these concerns, despite NHS policies of openness.
	Failure to include the family's views in the remit of the review: The Hart family believed that VP's level of experience was central to the quality of care that Averil received, but this did not feature in the remit, and we were given no opportunity to voice this concern. The remit was set by NNCCG, with reference only to a sub-set of questions asked much earlier. Although we asked for an opportunity to meet with Dr Vize, this was initially refused, only to be permitted at a later stage. By this stage, our concerns with the report's independence were too significant to partake in its process. We feel our views and questions were not respected by NNCCG.
	Further concerns with Dr Vize's report: We are concerned that Dr Vize's opinion is contradictory in parts, and does not adequately address a number of key issues raised in her conclusions. These will be detailed below.
	Failure to accurately record meetings: We have encountered significant problems with the proper recording of meetings. On the 10th March 2014, we met with NNCCG, but received a letter subsequently that did not reflect accurately the content of the meeting, containing only broad themes and NHS policy on the topics discussed. The specific promises made (noted by us) were nowhere to be seen.

	Inadequate responses to questions, not addressing subject matter: We received several responses to questions that did not directly address the subject matter posed, and which often omitted one element of a question at the expense of the other. This practice has rendered the process of finding out what happened to Averil much more difficult.
Cambridgeshire and Peterborough NHS Foundation Trust	**Failure to release Averil's full medical records:** When we applied to access Averil's medical records, we were sent only a small proportion of the four volumes that CPFT is recorded as holding. These records were selected by Jane Shapleske, who runs NCEDS, and who removed all but one document and two e-mails that she had authored, despite her extensive involvement at S3 ward. We discovered the extent of this editing on reading Dr Vize's opinion, which disclosed the full extent of the medical file, and some relevant information kept from us. A subsequent application for medical records has suggested to us that this may have been inconsistent with our rights under the Access to Health Records Act 1990, and evidence of professional misconduct.
NHS England (East Anglia)	**Failure to identify the substance of our complaint:** Our complaint about UEA Medical Centre was wrongly interpreted by NHS England East Anglia, and reduced to four bullet points, which reduced our complaint to the fact that UEA Medical Centre failed to undertake any monitoring of Averil. This was not the case. This was indicative of a failure to understand the serious nature of the failings of UEA Medical Centre that led to Averil's death.
	Failure to act on transfer of complaint to NHS England: Having transferred the complaint to NHS England, it appears no further action has been taken, despite this having occurred in January of this year. Seven months later, we have received no response.
Norwich and Norfolk University Hospital	**Inappropriate initial response to Concerns:** We submitted a formal complaint on 9th January 2014. The trust's response was inappropriate, simply explaining the care that had been provided to Averil. The letter also stated that MARSIPAN guidelines, on which the complaint was based, had been met. This was insufficient. Their statement that Dr Serfontein gave guidance on Averil's treatment did not match his own account of the telephone conversation that day, in which he was only informed that Averil had been admitted, and could not effectively advise on her treatment on the ward. This insufficiency was recognised by NNUH, and, in subsequent e-mails (Tab XX), failures were acknowledged. An independent review of treatment provided at NNUH was commissioned, and Dr Paul Robinson is leading.
	Administrational Issues in Complaints: Although the review was scheduled for July this year, Dr Robinson was not originally provided with a copy of the complaint submitted by the Hart family about Averil's care. We had to give him our copy, along with Dr Alan Forbes' chronology and commentary of treatment at NNUH. We think that this omission was reflective of poor organisation among the team.

Cambridge University Hospitals NHS Trust	**Failure to respond to our complaint in a commensurate manner:** Although a Serious Incident report was prepared into the treatment Averil received at Addenbrooke's, we submitted a complaint about the care she received on 9th January. The response to this complaint was unsatisfactory. We were told that the specific questions that we raised were addressed in the Serious Incident report, and no further investigation would be provided. This provided no recognition of the failings in Averil's care at the hospital, preventing enlightened improvements in future services.

Proposed Remedies: What would we like to happen?

Following Baroness Fritchie's review of the Ombudsman's procedure in 2012,[3] Julie Mellor wrote:

> *When people complain about the events leading to the death of someone they love, they often tell us that they want to achieve two things. They want to know what happened, and to make sure that changes are made to stop the same situation happening to someone else.*

This echoes the reasons for our complaint to the Parliamentary and Health Service Ombudsman. Since Averil's death, we have sought to clarify what went wrong with Averil's care, to obtain an apology for the mistakes made that led to her death, and to see evidence that changes have been made for the benefit of other patients in the future.

We would ask that the PHSO does its utmost to obtain the following on our behalf:

1. An acknowledgement from the NHS organisations involved that numerous serious mistakes were made in the care provided to Averil.
2. A sincere apology from these organisations to Averil's family, boyfriend and friends, for those mistakes that contributed to her tragic and untimely death.
3. Evidence that changes have been made for the benefit of other patients in the future, both at the level of service provision, and care commissioning.
4. Appropriate disciplinary action where the medical standards (GMC guidelines) have fallen below acceptable standards in Knowledge and Skills; Patient Safety; Quality of Care; Communication and Trust (including openness, honesty and integrity).

[3] Fritchie (2012) *Review of the Health Service Ombudsman's approach to complaints that NHS service failure led to avoidable death.*

Detailed Complaints Regarding Quality of Care

1. Discharge from S3 Ward

Averil was discharged from S3 Ward on 2nd August 2012. At this point, we believe that it was too early, and that Averil may have benefited from further inpatient treatment. We also believe that the risk assessment that was carried out was insufficient with reference to leading guidelines. Those involved failed to clearly state Averil's level of risk, and to communicate this risk to others, including her family who had placed their trust in the professional team. This endangered her, and meant that inappropriate treatment was provided after her discharge.

1.1. Averil was discharged too early from S3 Ward

Averil's target weight at discharge was 50-52kg, yet she was released at a weight of only 45.2kg. At this point, her weight gain had slowed, but this was not a reason to discharge her into an environment where she was likely to struggle more. We believe that Averil was not ready for discharge by the 2nd August, and that further inpatient treatment may have helped her.

Signs in Counselling Sessions

On **19th July 2012** Averil had an appointment with Sarah Beglin, her care co-ordinator. The session notes read as follows:

> *Anxious about driving to Norwich at weekend.*
>
> *Tempting to compensate by decreasing eating, but never really learn that it was okay.*
>
> *[Unclear: Bets – experiment?]*
>
> *"If I go to Norwich and don't compensate, my weight will shoot up." (i.e. by 7 kilos) trust because is meant to be increasing weight.*

This session, less than two weeks before she was discharged from the unit, suggests that she was not fully prepared for life as an outpatient. She had already admitted that she was "scared this date [August 2nd] is too soon but I think I need to go for it", but the statements made in that session, and the significant difficulties she still had while on home leave suggest that continued inpatient treatment would have been beneficial.

> **Evidential Difficulties:**
>
> Our copy of Averil's medical records does not contain any notes dated before the 19th July 2012, and our notes after this point may be incomplete. We await Averil's full medical records from S3 (pending release by CPFT) which may find further questions relating to her mental condition on discharge from the ward.

Signs in Averil's Weight Record

Averil's discharge summary explains that she struggled to manage her weight, and needed a high meal plan to gain weight. It states that her progress slowed as she lost motivation. However, there is

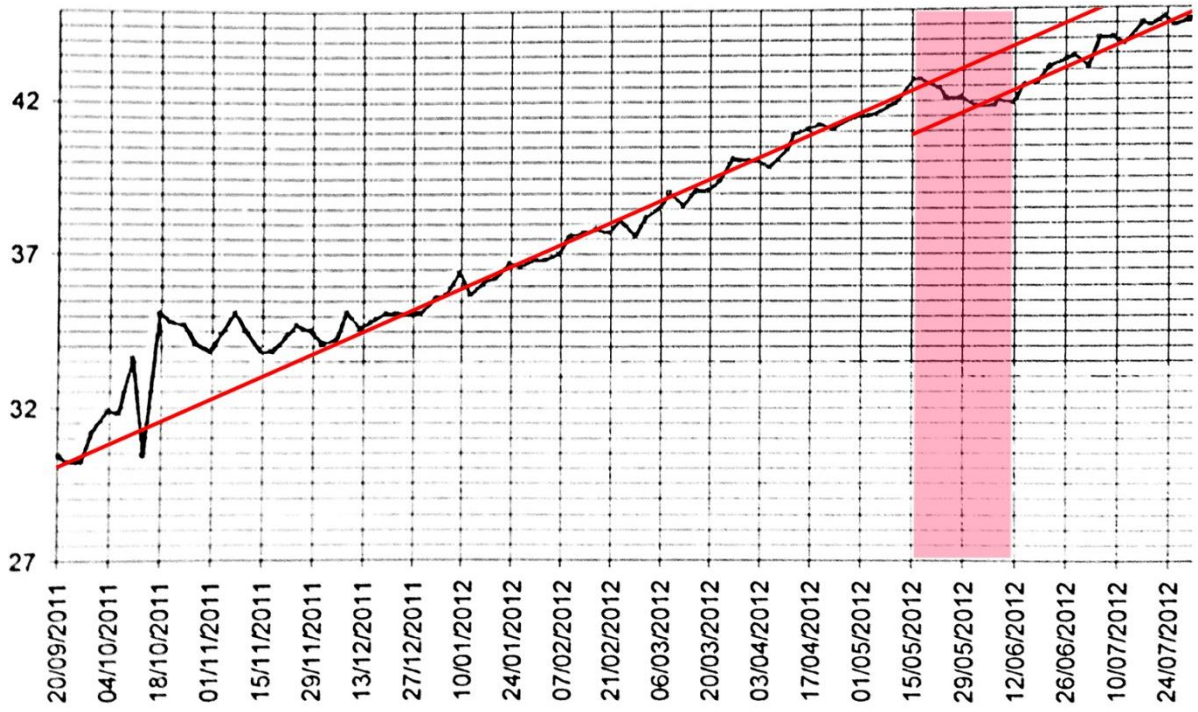
evidence in her weight history to suggest that the weight gain rate did not decrease, but suffered a setback during home visits from the ward. The small dip in May 2012 appears indicative of a temporary setback, rather than a loss of motivation.

> **Evidential Difficulties:**
>
> Although Dr Vize's Independent Professional Opinion mentions (para. 25) that the weekly management round on 28/02/2012 noted that she consistently lost weight on home visits, we do not yet have access to the medical records that confirm this. **We believe that Averil took home leave in May, which may account for some of the decline in weight experienced at that point. This should have been seen as a clear indication of future difficulties after discharge.**

During Averil's last weeks of treatment, her weight gain is similar in speed to the prevailing rate before the temporary plateau in May, suggesting that ongoing supervision has been effective, and that the slowing of progress mentioned is related to a specific incident, rather than a general lack of motivation to regain weight. This setback, which we believe was the result of home leave, should have acted as a warning sign, showing that Averil needed continuing inpatient supervision.

Finally, even at the point of discharge, Averil remained significantly below her target weight of 50-52kg, and significantly below the higher BMIs associated with improved recovery as an outpatient.[4]

Figure 1: Averil's Weight during Inpatient Treatment (September 2011 – July 2012)



Operational Considerations

In a meeting between Nic Hart and Jane Shapleske, JS discussed the fact that the unit was short of money, and that there were not enough beds available. They were stretched for resources. **We argue that operational factors were material in the decision to discharge Averil, compromising the safety of a recovering inpatient, who would have benefited from further supervision before University.**

[4] Rigaud *et al.* (2011) *Outcome in AN adult patients: A 13-year follow-up in 484 patients,* 37 J. Diab & Metabolism, pp.305-311

Freedom of Information Act requests regarding the cost of care at S3 and at NCEDS (submitted to CPFT) have not yet received replies, but it is certain that outpatient treatment is much less expensive than inpatient treatment. When Averil's weight loss was assessed as slowing, the cost of her further recovery, and of meeting her weight target, increased significantly in the estimations of those at S3.

1.2. S3 Failed to Undertake a Comprehensive Risk Assessment

Our initial complaint to CPFT regarding the failure to ensure implementation of a basic risk assessment received the following response:

> *A risk assessment was conducted at the CPA discharge meeting on 31 July 2012. Ongoing risk assessment also occurred during outpatient contact on 9 August and 30 August 2012 and during telephone contact on 27 September and 4 October 2012. The GP was written to on 27 September 2012 and informed of medical monitoring requirements.*

This, however, misses the point. We do not deny that a risk assessment took place on the 31st July 2012, or that the GP was written to. **Our complaint is that the content of this risk assessment failed to take into account the various sources of risk alluded to in the King's College Guidelines[5] and the NICE Guidelines.[6]** Assessing risk with reference to the context into which the patient is to be discharged (and clearly communicating overall risk levels) will be beneficial for future patients.

Averil's Risk Assessment

When Averil was discharged from S3 ward, the risk assessment (July 31st 2012) evaluated the physical risks to Averil's health and the psychological risks, which they deemed to be slowly improving. There was **no overall assessment of risk level.**

> *The **physical risk** has reduced to a minimum, but there could be mid and long-term risks such as osteoporosis… There are **psychological risks** associated with Averil's difficulty to experience "negative" emotions, as well as her difficulties with recognising eating disorder related behaviours, but these are **improving very slowly** with Averil's focus on these. There are no risks associated with suicide or deliberate self harm.*

We argue that Averil posed a high risk of relapse when she was discharged from S3 ward, and her outpatient treatment should have proceeded accordingly.

The Serious Incident Report commissioned by CPFT to investigate Averil's care highlighted that the risk assessment actually carried out was insufficient:

> *With omissions in assessing and thereby identifying AH's needs and risk **given her new situation** as a young woman entering independent living, away from her family who were acknowledged as pivotal in her support and care, having just spent eleven months in a structured inpatient environment.*
>
> *This lack of transition and care planning impacted on the level and nature of risk AH appears to have been identified as being at…*

In this section, we will aim to explain in what ways the content of the risk assessment was insufficient, with reference to guidelines, and with reference to Averil's situation as it was known to the clinicians who assessed her at the time.

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[5] Treasure, J. (2009) *A Guide to the Medical Risk Assessment for Eating Disorders.* King's College London.

[6] National Institute for Clinical Excellence (2004) CG9: *"Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders."*

Guidelines on Risk Assessment

The King's College Guidelines, to which Sarah Beglin specifically referred in her discharge summary, and which she sent to the relevant clinicians in Averil's case, state:

> *The factors involved in the assessment of risk in people with eating disorders include:*
>
> - *Medical Risk*
> - *Psychological Risk*
> - *Psychosocial Risk*
> - *Insight/Capacity and Motivation*

The risk assessment carried out for Averil covered psychological risk, touches on insight, but is incomplete in its analysis of her medical risk, and makes no mention of her psychosocial risk. The guidelines emphasise that measurement of medical risk through BMI alone has limitations, and that other factors must be taken into account:

> - *Excess exercise with low weight.*
> - *Factors which disrupt ritualised eating habits (journey/holiday/exam)*

In support of this, the NICE Guidelines also state:

> *1.1.1.1 Assessment of people with eating disorders should be comprehensive and include physical, psychological and social needs, and a comprehensive assessment of risk to self.*
>
> *1.1.1.2 The level of risk to the patient's mental and physical health should be monitored as treatment progresses because it may increase – for example, following weight change or at times of transition between services in cases of anorexia nervosa.*

The essence of these guidelines is that mental health and physical health must be considered first, but that external factors – social context, points of transition in life and treatment, family background – must be seen as moderating the level of 'clinical' risk, and must thus be included in the risk assessment.

Risk Assessment: The Whole Picture

We believe that risk assessment must consider three particular areas. First, **the patient** must form the centre of the inquiry, their history guiding the factors that are influential in the future. Rigaud et al (2011)[7] found eight factors particularly predictive of lack of recovery, of which five (bold) are likely to be visible in a patient history, even before treatment.

> *Eight factors were linked to the lack of recovery at 2 years: low BMI at discharge,* ***low energy/fat intakes****, high drive for* ***excessive exercising****, high score for* ***perfectionism,*** *for* ***interpersonal distrust*** *and for* ***anxiety,*** *use of tube-feeding and adhesion to treatment.*

In Averil's case, she had a low energy intake, and medical notes highlight her problems with exercise:

> *"Averil continues to identify that exercise is a big challenge for her, but has a 'really good plan' in place."* (with Zoe Brown, 31/07/2013)

[7] Rigaud *et al.* (2011) *Outcome in AN adult patients: A 13-year follow-up in 484 patients,* 37 J. Diab & Metabolism, pp.305-311

> *"Spent session talking about [decreasing] exercise and how anxious that makes her… Has progressed well – sitting down after meals + in evening."* (with Sarah Beglin, 19/07/2013)

Moreover, it is clear from the same notes that Averil was a perfectionist, and expressed significant anxiety, specifically about her move to university. She expressed this, along with particular intentions of continuing anorexic behaviour, in her counselling sessions:

> *Social Anxiety – I want to be funny… I'll be boring… Self-critical ++ What if people reject me? What if I'm not good enough? Not funny enough? Not witty, sparkling, entertaining. Too much pressure on me.*
>
> *Role of perfectionism… (with Sarah Beglin, 30/07/2013).*
>
> *"If I go to Norwich and don't compensate, my weight will shoot up. (I.e. by 7kilos)" (with Sarah Beglin, 19/07/2013).*

Averil's medical notes from her discharge at S3 also highlight another risk within her history: rapid weight loss. From the 10th to the 14th October 2011, Averil lost 3kg in weight, and this incident was reflected in her CPA Care Plan updated on the 31st July 2012:

> *Averil weight loss may be sudden, and she may become frail and prone to falls.*

Overall, we believe that Averil's history, and her anxiety about the future, indicated that the "patient" component of risk was elevated. Both the behaviours she displayed and the thoughts that she had about university were strongly linked to her condition, suggesting it had a significant hold on her, even at the point of discharge.

> **Evidential Difficulties:**
>
> We were deprived by Jane Shapleske of access to any notes from Averil's time as an inpatient, save brief notes from the last three days, somewhat inconsistently with our rights as executors under the Access to Health Records Act 1990. Our comments on the risk assessment are thus limited to the small amount of evidence that we have.

Secondly, the **environment** into which the patient is to be discharged will influence the level of risk they face. The environment includes the social dynamics of the patient's life – including work, education and social life – and the dynamics of the outpatient service into which they are being discharged.

There is clear consensus that points of transition between services are times of elevated risk for sufferers of Anorexia Nervosa, as explained by Treasure, Schmidt & Hugo (2005)[8] and in the NICE guidelines themselves:

> *The level of risk to the patient's mental and physical health should be monitored as treatment progresses because it may increase – for example, following weight change or* ***at times of transition between services in cases of anorexia nervosa.***
>
> National Collaborating Centre for Mental Health (2004)

As one form of treatment ends and another begins, the gap in between presents an opportunity for anorexic behaviours to recur, leading to weight loss and the re-establishment of routines and mechanisms that inpatient treatment may have sought to moderate.

[8] Treasure, J., Schmidt, U., Hugo. P. (2005) *Mind the gap: service transition and interface problems for patients with eating disorders,* 187 BJPsych, pp.398-400

Points of transition in other areas of life will raise risk significantly, and the high prevalence of Eating Disorders among late adolescents means that University life poses a particular challenge. Within NCEDS itself, referrals peak just after new University students arrive, while the charity BEAT runs a project designed to provide additional support for those moving to University. King's College Guidelines draw attention:

> *Factors which disrupt ritualised eating habits (journey/holiday/exam)*

Medical risk increases as meal patterns become disrupted, and the transition from home life to university is similar. Family routines, characterised by meals and the support of others are replaced by academic timetables, social and extracurricular activities, and unstructured time, which reduce opportunities for food intake, and leave the patient without familial supervision for the first time.

Health Service factors are also significant. While its inclusion in risk assessments may cause conflicts for clinicians, the nature of the service to which the patient is discharged may influence the risk decision regarding that patient. If a particularly long gap exists between referral and pick-up, this must be taken into account. Moreover, an assessment of the service itself must go beyond referral times, accounting for staff shortages, high case loads, or inexperienced staff, whether in primary care or secondary care.

While this information may not be available to all clinicians for referrals, where it is known, it is relevant and should be taken into account. For example, primary care practitioners understand that there is a greater need for physical monitoring in a patient whose risk level is elevated by chaotic secondary care.

In Averil's case, NCEDS and AEDS shared some staff members, and conditions at either unit were well known. In her letter dated 21/09/2012 Sarah Beglin mentions "new starters", referring to the new trainee psychologists due to arrive, and staff shortages and the difficulties encountered in finding psychologists have been referred to repeatedly in e-mails received from CPFT:

> *There were significant difficulties in recruiting staff to the team. NCEDS had undertaken several recruitment drives but had been unable to recruit sufficiently qualified and suitable staff.*

Finally, **condition-specific factors** must be borne in mind. Anorexia nervosa has significant co-morbidity. With a mortality rate estimated at 5.9%[9] there are significant risks to all patients discharged from inpatient units. This risk will, naturally, reach its peak at times when other risk factors are present.

There is a significant risk of relapse among Anorexia Nervosa sufferers. Carter *et al.* (2012)[10] find that relapse occurs in 41% of patients after weight restoration to a BMI of 20 in Inpatient Treatment. This was predicted by, among others, a decrease in motivation to recover during treatment. A 13-year follow up by Rigaud *et al* (2012)[11] found, additionally, that the relapse rate was around 56% at 1yr in patients discharged at a BMI of 15.5-16.5, but it was less than 18% for those discharged at higher than 18.5. We can only speculate as to the change in outcome that continual inpatient treatment until a BMI of 18.5 could have produced.

Conclusion

The particular nature of Averil's history, her personal life, and the service to which she was being discharged all contributed to a state of significantly elevated risk on discharge from S3 ward. Although no overall risk level was indicated, Sarah Beglin warned the UEA Medical Centre of her vulnerability, her fragility, and the need for careful medical monitoring as a result. It was a 'dangerous time' for Averil,

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[9] Steinhausen, H.C., (2002) *The outcome of anorexia nervosa in the 20th century,* 159 Am J Psychiatry pp.1284-93

[10] Carter *et al.* (2012) *A prospective study of predictors of relapse in anorexia nervosa: Implications for relapse prevention.* 200 Psychiatry Research, pp. 518-523

[11] Ibid, n.4 (above).

and her treatment should have reflected this. CPFT's Serious Incident Report concludes that Averil should have been identified as high risk to enable discussion at the appropriate time in team meetings. Despite explicit findings that Averil was high risk, her risk was not updated or communicated correctly.

1.3. Failure to Update Risk Assessment throughout Treatment

The classification of Averil's risk has been a continuing issue with both CPFT and NNCCG. Averil's risk was not fully assessed on discharge, but indicators of high risk were given to UEA Medical Centre. Several points can be identified where Averil's risk was either assessed or hinted at, but these display a worrying lack of consistency between assessments, both before and after her death:

- On discharge from S3 ward, Averil's risk was not fully assessed. The risk assessment simply noted several sources of risk.
- On 27th September 2012, Sarah Beglin phoned Dr Kevin Burgess at UEA Medical Centre, noting that she is **still regarded as fragile,** and that a new start at Uni could be a **potentially dangerous time for Averil.** She had lost some weight since her discharge, **she has been out a few weeks and is vulnerable at the moment.**
- On a document dated 13th November 2012, written by VP, the box **"High Risk"** is ticked with the words **"on own, relapse possible"** added to it.
- On 4th December 2012, Averil was discussed at the NCEDS team meeting under the heading "Patient Concerns / High Risk." At this point, the concerns of Averil's father were noted.
- In the Serious Incident Report prepared by Tony Jaffa at CPFT, they conclude that "the lack of transition and care planning impacted on the level and nature of risk [identified in Averil's case]… compounded by AH not being included in the team processes in operation at the NCEDS to **ensure multi-disciplinary discussion of high risk cases which AH was one of."**
- On 3rd October 2013 a letter was sent from CPFT to NNCCG, in which Chess Denman, Clinical Director at CPFT, states that "from the documents from the ward it was deemed that Averil was not high risk."
- On 22nd May 2014, Aidan Thomas wrote that Averil's risk "was not determined to be high".
- Independent Professional Opinion of Dr Christine Vize:
    - Para 111-112: Dr Vize concluded that the risk on discharge was "medium." She also added that at some point the risk changed from "medium" to "high".
    - Para 169: Dr Vize refers to "Patients designated as high risk" as those at "BMI <15", suggesting that she was such a patient at all sessions with VP.

If Averil's risk assessment was changed from high (on discharge) to low, who was responsible for the change? Who authorised it?

This chronology suggests that no overall evaluation of risk was made before Averil's death, despite the fact that several care plans were drafted, and certain documents draw attention to her "high risk of relapse". However, further to this error, risk information appears not to have been shared between the appropriate agencies (UEA Medical Centre and NCEDS) or within them, with no account being made of changes in risk level within team meetings. The result of this confusion was that Averil's need for urgent medical assessment went unnoticed throughout November, despite her rapid physical decline.

This is echoed in the findings of the Serious Incident Inquiry carried out by CPFT:

> *With omissions in assessing and thereby identifying AH's needs and risk given her new situation as a young woman entering independent living... This lack of transition and care planning impacted on the level and nature of risk AH appears to have been identified as being at, and was compounded by AH not being included in the team processes in operation at the NCEDS to ensure multidisciplinary discussion of high risk cases which AH was one of.*

Measuring Risk of Relapse in Averil's Case

Effective risk assessment includes the patient, the service and the condition itself.

Averil had several factors in her medical history that emphasised the difficulties she would face on discharge. These should have translated into a high risk discharge summary.

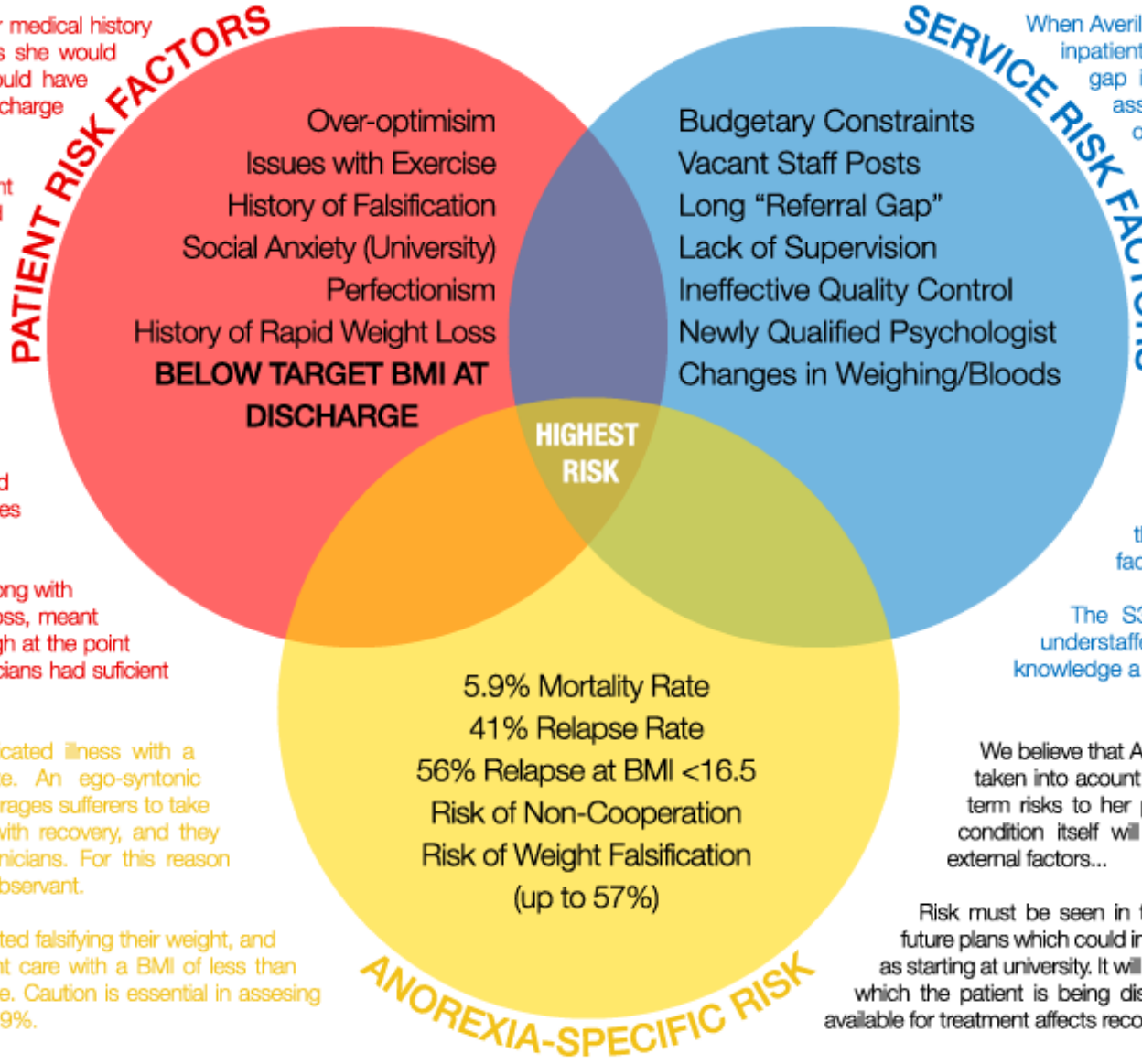
Averil had a history of weight falsification as an inpatient, and the behaviour is more prevalent among outpatients. She also had significant issues with exercise, using high levels of activity to compensate for her food intake.

Notes from sessions with a psychologist at S3 and in transition show that Averil had strong perfectionist tendencies and social anxiety.

These psychological factors, along with her history of sudden weight loss, meant that Averil's risk was already high at the point of discharge, and that her clinicians had suficient information to know so.

Anorexia Nervosa is a complicated illness with a particularly high mortality rate. An ego-syntonic condition, anorexia often encourages sufferers to take actions that are inconsistent with recovery, and they often actively deceive their clinicians. For this reason clinicians must be careful and observant.

Up to 57% of outpatients reported falsifying their weight, and those discharged from inpatient care with a BMI of less than 16.5 were most likely to relapse. Caution is essential in assesing risk, as mortality is as high as 5.9%.



When Averil was discharged from S3, a close inpatient environment, to a two month gap in outpatient treatment, the risk assesment made ignored the effect of the gap between referral and treatment and the additional risk posed by the high case load at NCEDS. The gap exacerbated the psychological risks faced by Averil during that time.

After treatment began, the service also failed to account for the extra risk introduced by the lack of physiological checks being carried out at UEA Medical Centre. This meant that no regular "medical" monitoring took place, raising the level of physical risk that Averil faced alongside psychological risk.

The S3 staff knew that NCEDS was understaffed, and should have made this knowledge a part of their risk assesment.

We believe that Averil's risk assessment should have taken into acount more than just the long and short term risks to her physical health. The nature of the condition itself will influence both of these, as will external factors...

Risk must be seen in the context of the present and of future plans which could influence the patient's risk level, such as starting at university. It will also be influenced by the service to which the patient is being discharged, as the quality and time available for treatment affects recovery.

2. Transitional Care

During Averil's transitional care between inpatient and outpatient services, a "transitional" arrangement was reached, whereby Sarah Beglin would monitor Averil's psychological wellbeing, and Averil would be physically monitored by her GP at home in Suffolk. This arrangement was designed to cater for specific needs, but basic elements of future care were compromised by the failure to carry out a recorded handover meeting and administrational issues. Our grounds of complaint include:

- Failure to hold a handover meeting, creating confusion among care providers, including UEA Medical Centre.
- Failure to include the family in this process, providing them with contact details and recording the means by which they could be contacted.
- Failure to learn from prior deaths and near misses within the service's predecessor.

2.1. Failure to Carry Out a Fully Recorded Handover Meeting

There can be no doubt that transitional care for a recovering Anorexia Nervosa patient is important, the MARSIPAN Guidelines' introduction to transfers between services emphasises this:

> *Patients being transferred from one service to another, whether it is SEDU to medical, vice versa, or from children and adolescent to adult psychiatric services, are vulnerable and special care is required to make sure the transfer is safe. Patients sometimes try and sabotage a transfer (e.g. when they realise that another place has a better chance of achieving weight gain) by engaging in behaviours that result in them becoming so ill that transfer becomes impossible. Moreover, staff in one unit may have information about a patient which may be lost in the transfer. Many of the problems can be avoided by adequate communication (Box 3).*

Averil's transitional care was a function of her being due to go to university less than two months after discharge. She was to be taken care of by Sarah Beglin, her care co-ordinator at S3, and by her GP in Suffolk, who would undertake physical measurements. This arrangement is detailed in the **discharge summary** (CPA Part II) as follows:

> *Averil will continue to work with Dr Sarah Beglin until she starts her English Literature and Creative Writing degree at UEA…*
>
> *GP: Please check Averil's physical health every week (weight, BP, heart rate and level of physical strength – Squat test). This can be done by a nurse. Please monitor her bloods every 2 to 3 months including U&Es, bicarbonate, LFTs, bone profile, muscle CK, Magnesium and Phosphate.*

This was sufficient to instruct Averil's GP in Suffolk. However, the further handover arrangements that took place in relation to Averil's GP in Norfolk (following her registration) were unsatisfactory. They took place by telephone only, and were not fully documented. The result was that confusion in the discharge notes could not be discussed, and no consensus could be reached, clearly defining who had the responsibility for which tests, and how often those tests were to be carried out.

The discharge summary, signed by Dr Tom Spencer and Dr Jane Shapleske, required that the GP check Averil's "physical health" every week, including (i) weight, (ii) blood pressure, (iii) heart rate and (iv) squat test. However, in the CPA Care Plan (Part I) prepared on her discharge from Addenbrooke's, the instructions are different, making no reference to the other physical tests.

> *To be weighed weekly and to have bloods every two months during the early stage of discharge and at University.*

These instructions also make no reference to the means by which the results were to be communicated, or how the secondary care team could access them. In addition, it appears that there was no medically qualified member of staff at NCEDS who could review these results and discuss them with VP and her supervisor. This, in itself, will have been a source of confusion. The GP in Norfolk then also received a summary of Averil's care plan, prepared by VP:

> *Given your BMI it is important to continue the regular medical monitoring with your GP. I would suggest however that whilst regular monitoring of your BP [blood pressure] is important to continue, these GP visits do not need to include taking your weight.*

The day before this communication, Dr Clarke at UEA Medical Centre had carried out all four tests for the first time. However, following receipt of the letter, that same doctor met with Averil, took her pulse, but did not carry out other tests. After that appointment, a note appears in her medical file "review in a month." It is clear that the importance of medical monitoring had been lost on UEA.

The result of this communication is that the other tests – pulse, squat tests – were only carried out once (before this letter was received), and there was no evidence in Averil's full care plan that they were needed. In Averil's last GP appointment on the 8th November, only her pulse was taken, and the note "review in a month" was added.

In Averil's last care plan, prepared by VP on 22nd November, no mention was made of the need for physical monitoring by a GP. At this point, it appears no attempts were made to ascertain if the medical tests were being carried out, and no tests were, in fact, carried out, suggesting a lack of supervision and experience in the role of care co-ordinator.

At the last full appointment on 26th October, all four tests – weight, blood pressure, heart rate and squat test – were carried out by Dr Clarke. The results of these tests, despite including a consistent weight, picked up a decreased blood pressure, at 95/65 mmHg, down from 103/67 mmHg. Whether this was evidence of the beginning of a decline could only have been ascertained by comparison to regular tests thereafter.[12]

These events demonstrate the need for a formalised handover procedure, accurately recorded, and with the involvement of all relevant care providers. This requirement is visible in guidelines produced for eating disorder patients. Our initial complaint relied upon the MARSIPAN guidelines, which state:

> *When a patient is transferred from one service to another there should be a properly conducted and recorded meeting between representatives of the two services, usually also including the patient and family, so that it is very clear what will happen during and after the transfer of care, and who is responsible for what. Such meetings should be continued until transfer is satisfactorily achieved.* [MARSIPAN, Box 3: *Transfer Between Services*]

This was rejected by CPFT: "As Averil was being discharged from a specialist inpatient unit and was above a BMI of 15, the MARSIPAN guidelines would not have been relevant in this discharge situation."[13] However, similar requirements are found in the NICE Guidelines:

> *Where management is shared between primary and secondary care, there should be clear agreement among individual healthcare professionals on the responsibility for monitoring patients with eating disorders. This agreement should be in writing (where appropriate using the care programme approach).* [NICE 1.1.1.4]

[12] It is worth noting that no reference was made to the need to check both standing and sitting blood pressure to identify postural hypotension, a key indicator of physical weakness as a result of anorexia nervosa.

[13] AT_Letter_to_NH_220514.pdf – Letter from Aidan Thomas to Nic Hart, responding to complaint submitted about transitional care provided to Averil.

It is almost certain that a better handover would have prevented confusion as to the physical tests to be carried out by the GP, and when blood tests should have been ordered. It should be noted that no blood tests were carried out in the four months between the 31st July and the 7th of December, when Averil was admitted to hospital. Even though the discharge was somewhat irregular, a meeting in which the concerned parties could discuss the care of their patient would have resolved any confusion created by the differing care plans and ad-hoc arrangements.

We believe that a better hand over may have prevented the loss of contact with Averil's GP, and thus her physical monitoring may have been markedly different.

We do not accept that a technical inapplicability of particular guidelines obviates the need for a proper handover meeting, and we suggest that it is implemented as standard in the future.

Failure to Obtain Relevant Contact Details

In our original complaint to CPFT we argued that the failure to provide the family with emergency contact details for NCEDS proved disastrous in an emergency situation. We still believe that this is the case. Although the family were present at the discharge meeting, the inclusion of emergency contact details as a matter of course would not be difficult or time consuming. The details that were available to us – the telephone number of S3 Ward – had only been taken down as a matter of chance.

During transitional care, the details of Averil's family and Averil herself were not collected or checked. In the last weeks of her care, this caused significant concern – Averil's mother received a phone call from VP on the 3rd December 2012, requesting Averil's mobile number. **We would strongly suggest that patient contact details are checked at the commencement of treatment on the basis of this experience.**

Ongoing Concerns as to Quality of Notes

In our original complaint to CPFT we raised the failure to document the appointment and handover to the new care coordinator to an acceptable standard. The SI report also contained similar concerns, and the response from CPFT acknowledged this was the case:

> *The documentation of this could have been improved and steps have been taken to ensure that this is the case. For example, at discharge meetings S3 now ensures that the care co-ordinator is always present or represented. In addition to this NCEDS undertakes an assessment of an individual irrespective of whether the patient is known to the CPFT eating disorder service.*

This does not answer our concerns as to documentation. While a joined-up meeting is likely to improve the quality of information sharing, and assessments of individuals at NCEDS are likely to prove beneficial, they say nothing as to the quality of the documentation.

Failure to Consider Previous Case Histories

We are aware that NCEDS itself was established following the death of Charlotte Robinson, but raised concerns in our complaint that the new organisation, despite its differing structure, had not responded to the events. CPFT responded:

> *Whilst I appreciate your very valuable feedback regarding the tragic death in 2008 this precedes the inception of NCEDS, and occurred in a service which was completely different in model.*

In early December 2011, at one of the regular family days held at Douglas House while Averil was an inpatient at S3, Averil's parents met several other families whose daughters were being treated on the ward. These families expressed concerns that their daughters had suffered "near misses" as

outpatients, and they felt that other patients may still be in danger within the service as a result. These concerns, however, related to the predecessor to NCEDS. We were all assured that changes had been made, that lessons had been learned, and that the newly restructured service was fit for purpose. It has not lived up to this promise.

We re-iterate our concern that CPFT has not learned from these cases, and that the failures that led to the 'near misses' under the old system have not been adequately remedied.

2.2. Failure to fill the "Care Gap" between S3 and NCEDS

During the months of August and September, transitional care arrangements were made in order that Averil did not have to re-engage with Suffolk's eating disorder services. Averil was to be weighed regularly by her GP, and would see Sarah Beglin on a regular basis. During this time, it appears that her care was not co-ordinated effectively, and the records indicate that both physical and psychological monitoring were sporadic.

Sarah Beglin took on the role of care co-ordinator for Averil during her transitional care, which involved responsibility for Averil's psychological monitoring. However, the records of this phase in treatment are sporadic, suggesting that few appointments took place:

- 9th August 2012 – Counselling session – Averil reported being "a bit flat" and her boyfriend was speaking to her again after she stopped speaking to him.
- 30th August 2012 – Counselling session – Discussion of how to go about making change, setting small goals and rewards.
- 12th September 2012 – Counselling session cancelled by Averil.
- 20th September 2012 – Counselling session – Discussed going to university, possible note of weights of 42.1kg and 42.6kg.
- 27th September 2012 – Telephone call – Discussed move to university as going well, no routine yet and GP appointment booked.
- 4th October 2012 – Telephone call – Discussed setting goals for wellbeing, weight noted as "going down".

This suggests that between 2nd August and 19th October, Averil had five points of contact with Sarah Beglin – this equates to once a fortnight. Most significantly, there was a gap of over two weeks between Averil's last telephone call on the 4th October and her first NCEDS appointment on 19th October. There appears to be little coordination at this time between Dr Beglin and Averil's GP in Suffolk, and clear weight measurements are not noted with dates in the file.

The gap complained of took place at the most vulnerable point in Averil's transition, as she settled down to University and prepared for appointments at a new service. At this time, Averil's anxiety was high – she was anxious about meeting a new therapist who would demand change:

> *I know this lady next week will want me to change my routine … it scares me. I want the freedom but not the pain of getting there.* (9th October)

We have received no explanation for the cessation of telephone contact, but believe that this tailing off of contact left Averil without the necessary support as she started at university, damaging her chances of recovery in the weeks that followed.

3. Secondary Care: NCEDS

Averil's treatment at NCEDS started after a significant delay, during which Averil's weight declined significantly. When her treatment started, she was assigned an inexperienced, newly qualified psychologist to co-ordinate her care. This psychologist was ill-equipped to deal with a fragile, high-risk patient. Unfamiliar with the physical signs of anorexia, she failed to notice that Averil was engaging in weight-falsification, meaning that her significant weight loss went unchecked. Continued physical monitoring by her GP, including taking her weight, would have increased the likelihood of Averil's weight loss being noticed in time to prevent her collapse.

We argue that this delegation of care was irresponsible, as the trainee took many inappropriate decisions. However, it was also NCEDS' failure to supervise her that led to a very significant deterioration in Averil's illness without adequate and ongoing risk assessment. This proved instrumental in her death. Our complaints relate to:

- The death of Averil Hart as a result of Anorexia Nervosa, a treatable condition that NCEDS had been specifically engaged to treat.
- Delays in the commencement of treatment leading to a significant decline in Averil's weight.
- Appointment of an inexperienced, newly qualified psychologist to manage Averil's care.
- Decision of the psychologist to take on responsibility for physical monitoring without training in weighing or monitoring patients.
- Failure of the psychologist to notice Averil's falsification of her weight, despite clear physical signs and lack of weight progress, alongside other anorexic behaviours (see weight graph).
- Failure to plan for a period of absence, during which the risk of rapid weight loss was elevated, permitting a significant decline.
- Failure of NCEDS to supervise their inexperienced, newly qualified member of staff with reference to points 2-5.
- Failure of NCEDS to respond appropriately to an **emergency** call, and to the report that their patient had been admitted to an emergency ward at NNUH.

3.1. Death of Averil Hart

Averil left for University in September 2012, but never came home for Christmas. The most important element of our initial complaints against the NHS organisations involved in her care is that Averil died while they were looking after her.

We were given assurances that Averil would be well cared for at University, both by the primary care team at UEA Medical Centre, and the secondary care team at NCEDS. It is clear from this outcome alone that there were failures in the care that they provided. **Their patient, Averil, died from a treatable condition which NCEDS had been specifically engaged to treat.**

3.2. Delays in Commencing Treatment

The draft service specification for Community Eating Disorder Services requires that patients referred to them are assessed within 28 days. For those designated "priority", treatment should start within 12 weeks, while those designated "urgent" start treatment in 2 weeks. Averil was not designated under either category, but a letter from Sarah Beglin to Madeleine Tatham on the 21st September 2012 expressed concern that Averil was picked up as soon as possible:

> *She is still struggling with a number of areas, specifically around reducing her exercise / activity levels, eating out and being flexible in her routines… I explained to her that… I would attempt to bridge the gap until she could be allocated a therapist… It would be good to add her to the list for the new starters as I think she does need to be picked up for CBT as soon as possible.*

There was, however, a significant delay in "picking up" Averil's case. From the first referral letter (sent 31st July 2012) to the first treatment session (19th October 2012) there was a significant gap, with Averil's case seemingly dependent on the appointment of a new staff member. From her last recorded session with Sarah Beglin (20th September), there was still a full month's gap before treatment. This left Averil without the reassurance offered by face-to-face counselling therapy each week, while she was at the most vulnerable point in her transfer to university.

3.3. Appointment of an Inexperienced "Trainee" Psychologist

As a newly qualified counselling psychologist, VP had little experience of the treatment of Anorexic Patients, and was new to the unit, and new to the NHS itself. Although we still believe that Averil should have been designated a "high risk" patient, even at a medium level of risk, her case was still complex, and required careful management. We asked CPFT what clinical experience VP had, and what experience she had of Eating Disorders. On 3rd October 2013, Chess Denman wrote:

> *The NCEDS Care Coordinator had experience of working with a small number of patients with a variety of eating disorder diagnoses **(not including Anorexia Nervosa)** during her Doctorate in Counselling Psychology training course. She had also attended a specialised eating disorder workshop prior to joining the team.*

VP had no experience of Anorexia Nervosa prior to treating Averil. Although she had attended a workshop, it is unlikely that this could have given her the preparation needed for dealing with the complexities of a disorder that makes trust difficult, and monitoring essential.

By appointing VP to be Averil's care co-ordinator, NCEDS placed the entirety of Averil's wellbeing into the hands of a part-time (0.8 whole time equivalent) member of staff, and should have supervised her to a greater extent, especially during the first weeks of her time at the service. Although regular meetings with MT took place, these were based entirely on VP's accounts of dealing with her patients, meaning that any factors not picked up by VP, including vital risk factors, could not be discussed. This limited the evidence from which clinical decisions and advice could be provided due to the lack of physical, medical and psychosocial monitoring.

By appointing someone newly qualified, new to the NHS and new to the treatment of Eating Disorders to provide Averil's care, NCEDS failed to provide adequate patient safety. The result was that her decision to take on medical monitoring went unchallenged, and her inexperience and lack of training consequently meant that physical signs of deteriorating health went unnoticed. **NCEDS failed to compensate for the increased risk that this posed to Averil's condition, and failed in their supervision to enquire as to the checks that were being carried out.**

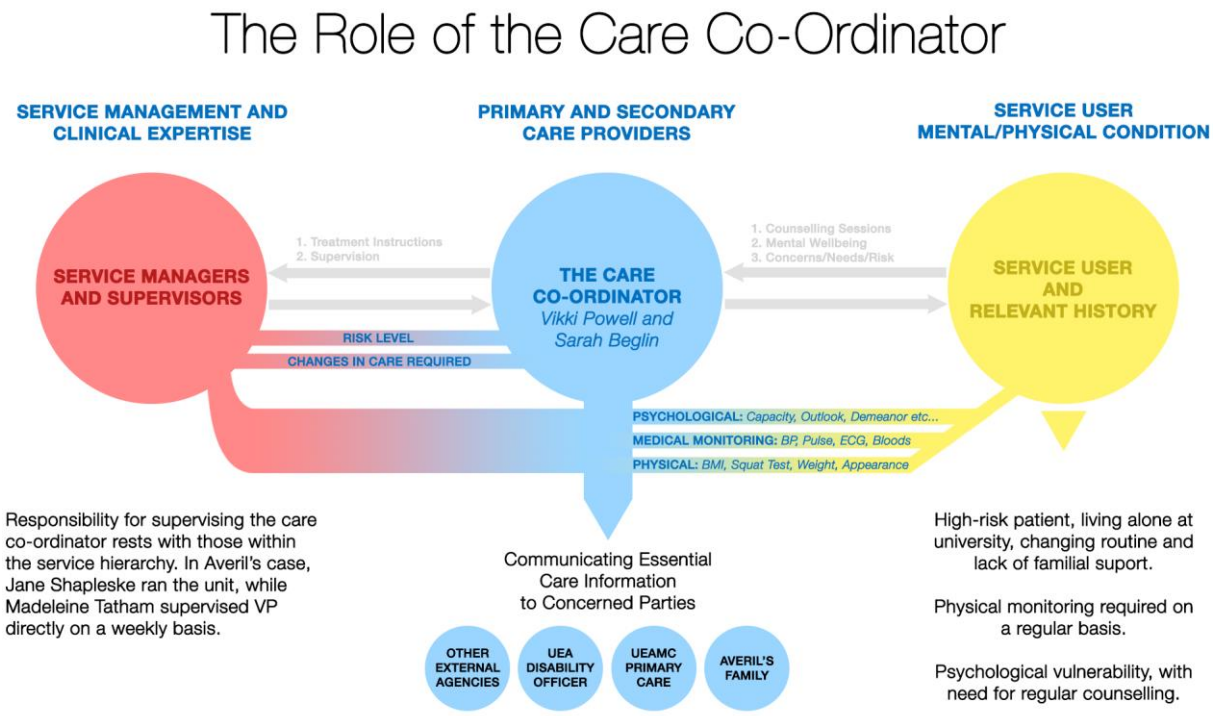
Our view is consistent with that of the Serious Incident Investigation Team at CPFT:

> *The allocation of a newly qualified Counselling Psychologist with very little clinical experience in eating disorder and of undertaking the role and responsibilities of care co-ordination was not, in the view of NCEDS and AEDS clinicians interviewed, ideal but was felt to have been clinically appropriate. **The view of the investigating team was not in accord with this view and consider that it is questionable as to whether it was appropriate for a newly qualified member of staff with such little experience in the specialism to be allocated as the sole eating disorder professional actually in face to face contact with a service user with a history of such serious eating disorder.***

Although in the Independent Professional Opinion commissioned by CPFT, Dr Vize concluded that VP was "qualified but inexperienced", we believe it is her experience that was relevant. She had no experience of the NHS organisations involved, had never worked with Anorexic patients, and had no experience or training in coordinating medical care. These factors made her an inappropriate choice.

3.4. Delegation of Care Co-Ordinator Role to an Inexperienced Candidate

The care co-ordinator acts as the main conduit of information, both between the service user and those that treat them, and between those providing treatment and the service responsible for their care. The diagram below (Figure X) attempts to illustrate this in practice. We believe that VP was insufficiently qualified to undertake this role, and that she failed to carry out the full extent of her duties under it.



The care co-ordinator's role is set out in CPFT's "Care Programme Approach Policy" (Tab 10):

> ***The Care Coordinator must:***
>
> *Ensure a systematic assessment of the person's health and social needs is carried out initially and again when needed (including an assessment of risk and any specialist assessments) and that the person's CPA level of need is identified.*
>
> *Coordinate the formulation and updating of the care plan, ensuring that all those involved understand their responsibilities and agree to them…*
>
> *Organise and ensure that reviews of care take place, and that all those involved in the service user's care are told about them, consulted, and informed of any outcomes. Chair the reviews if appropriate.*
>
> *Identify unmet need and communicate any unresolved issues to the appropriate managers, through the appropriate systems.*

These instructions demonstrate clearly that the role of the care co-ordinator is to bring together all elements of that individual's care, organising the communication between the relevant agencies.

VP, a newly qualified psychologist, had limited experience of the NHS and the organisations involved, and was ill placed to act as the main facilitator of communication between them. As will be explained below, no direct contact with UEA Medical Centre took place in order to check that the required tests had been carried out.

Moreover, when Nic Hart called S3 to warn of Averil's condition on the 28th November 2012, and VP was notified, she did not alert UEA Medical Centre of this call. The Centre remained unaware of the emergency call until Averil's admission to Hospital. Had VP checked that tests were being carried out, she would have found that they had not recently seen Averil, and may have been more alert to her actual condition.

A further pair of instructions clearly states:

> *Take responsibility for ensuring continuity of care, using home visits, repeat appointments etc. Providing clear written instruction on how to contact team members responsible for aspects of the care are made available to all those who need them.*
>
> *Arrange for someone to deputise if absent, and pass on the Care Coordinator role to someone else if no longer able to fulfil it.*

As will be explained below, VP failed to deputise her role when absent, with drastic consequences. She clearly failed to follow the Trust's own policy on care co-ordination, and the result was that Averil died while under her care.

3.5. Decision of Psychologist to Undertake Weighing

On 27th September 2012, Sarah Beglin phoned the UEA Medical Centre, speaking to Dr Kevin Burgess:

> *[Averil] is still regarded as fragile, new start at Uni could be potentially dangerous time for her. Averil has lost some weight since her discharge, she has been out a few weeks and is vulnerable at the moment.*
>
> *Dr Beglin would like the safety net of medical centre, and hopefully a* ***named GP for her.***

It is clear from these instructions that Dr Beglin saw the monitoring of Averil's physical condition as paramount, and assessed her risk of relapse as significant enough to warrant careful medical supervision. The request for the "safety net" of the medical centre suggests that the physical monitoring of Averil's condition could help prevent a significant decline, and the hope of a named GP highlights the desire for consistent contact with an individual qualified to make a medical assessment.

In her first appointment with VP, Averil noted the discrepancy between the weight recorded at UEA Medical Centre on the 12th October (41kg) and at NCEDS on the 19th (39.2kg). From the 29th September (42.2kg at UEA Medical Centre), there had been a 3kg loss, roughly 1kg per week. *This was significant enough to reach the "alert" point in the King's College Guidelines.*

In contrast to raising any form of alert, the psychologist's response was to effectively decrease Averil's medical monitoring. In her letter to Averil, dated 30th October 2012, she instructs the GP that:

> *I would suggest however that whilst regular monitoring of your BP is important to continue, these GP visits do not need to include taking your weight. That can be completed at our weekly sessions, and avoid the confusion of daily fluctuations in weight and between differing scales.*

We argue that this decision was inappropriate and endangered Averil.

While VP had a doctorate in psychology, and was familiar with CBT and other treatment methods for counselling patients, she was trained as a counselling psychologist, and CPFT has released no evidence to suggest that she had training in the physiological monitoring of patients, whether through careful history-taking, weighing or visually assessing their appearance. Without knowing the signs to look for, VP would be unlikely to identify risk factors.

Moreover, her letter added to confusion at UEA Medical Centre. While on the 25th October they carried out a squat test alongside weight, blood pressure and pulse measurements, when weighing was declined on the 8th November, only a heart rate was taken, and the note "review in a month" was added. By taking the main responsibility for Averil's physical health away from the UEA Medical Centre, VP created the impression that their monitoring tasks were not of particular importance. This meant that other parameters were not checked, and the information that could have alerted both primary and secondary carers to a serious decline in her health was unavailable. We feel that these actions illustrate inexperienced and badly supervised care coordination.

3.6. Failure to confirm medical monitoring at UEA Medical Centre

Having taken responsibility for Averil's weight monitoring, VP then failed to ascertain that further tests were being carried out. After her appointment at UEA Medical Centre on the 26th October, only one further appointment took place, at which Averil's heart rate was recorded. There is, after this date, no discussion of GP monitoring anywhere within the medical record.

We argue that VP should at least have verified that Averil was attending UEA Medical Centre in her capacity as Averil's "Lead Clinician" and "Care co-ordinator." By failing to verify that other checks were occurring, she placed Averil's ongoing health in jeopardy.

We complained to CPFT that NCEDS had failed "to verify with the primary care team that the weekly patient health checks were carried out." The response was as follows:

> *See 2.0 above. Clear instruction was provided to Averil's GP on 27 September 2012 regarding her treatment requirements.*
>
> *[In attached document…] "A copy of Averil's letter was sent to the GP on 26th October 2013 from her therapist to remind them of the necessity for medical monitoring."*

This, however, was not our concern. The failure to **verify** with the primary care team that weekly health checks were carried out is a **failure of the care co-ordinator** in their role, which involves ensuring that both mental and physical health is maintained. As is apparent from Averil's medical notes, after the letter sent to the GP, only one heart rate check was carried out. In a letter dated 3rd October 2013, Chess Denman explained what monitoring took place:

> *The NCEDS care co-ordinator asked Averil at each appointment whether she had attended medical monitoring and was informed by Averil that this was occurring. The NCEDS Care Coordinator did not liaise with the GP surgery to check whether this was the case. Contemporaneous notes suggested that she was attending medical monitoring prior to first therapy session at NCEDS.*

VP's notes in the medical file do not appear to include Averil's responses to the medical monitoring question, and references to the Medical Centre are minimal. Despite this, the notes from her first session mention that "Averil asked about the need to attend GP monitoring weekly still."

This demonstrates that VP already had notice of Averil's urge to end the weekly physical monitoring sessions at the Medical Centre. This knowledge made her aware of the specific need to liaise with the primary care team. However, she appeared not to continue to check that the tests were occurring, nor to check the results of the tests carried out there.

By not verifying directly with UEAMC that Averil's physical health was being monitored after issuing the *prohibitively vague* instructions in her letter, VP failed to carry out the duties of a care coordinator, which include facilitating inter-agency communications.

3.7. Failure to Notice Weight Falsification and Physical Changes

By sending a letter to UEA Medical Centre to stop them weighing Averil, VP assumed responsibility for monitoring Averil's weight. However, she had no training in doing so, and seems to have been unaware of weight falsification techniques. Without medical qualifications, she was unable to monitor for other physical signs of deteriorating health.

Weight Falsification

The accurate recording of weight for Anorexia Nervosa patients is of paramount importance. A 2011 study by Tony Jaffa[14] noted that in inpatient settings, 30% of patients report weight falsification, but for outpatients, 57% are recorded as doing so. It is, on that basis alone, more likely than not that Averil engaged in some form of weight falsification. These techniques involve:

> *…falsifying weight by means such as drinking water before weighing, wearing weights or other items and gripping the weighing machine with long toes to increase weight...* (MARSIPAN, 2010 at p.25)

We believe that Averil was engaging in weight falsification techniques, and that the NCEDS team was unprepared for them, despite their prevalence, and despite warning signs.

The risk of falsification is well known within clinical circles, and within CPFT itself. The MARSIPAN guidelines begin their section on behavioural management with the following statement:

> *If weight gain is less than expected, suspect that something untoward is going on.*
>
> *MARSIPAN,* Box 8: Behavioural Management of Patients with Eating Disorders

Where a patient's weight does not appear to match recorded intake, questions must be raised. In Averil's case, there is evidence from the medical file alone that Averil's weight gain was less than expected, yet this is "rationalised" away. On the 26th October, VP noted that Averil's intake was insufficient to raise weight, but her weight increased anyway:

> *Overall, Averil is aware that total intake is not sufficient to effectively increase weight. Predicted loss of weight but 0.4[kg] increase (BMI 14.56)*

Conversely, on 23rd November 2012, Averil's last session, VP notes:

> *Averil was very disappointed when she saw weight loss of 0.4kg to 38.2kg. In making sense of [that week's] recorded increase in intake but weight loss, Averil admitted to doing more formal and informal activity than always revealed.*

Here, on the face of the medical record, Averil admits to dishonesty in her accounts of exercise, suggesting at least one form of dishonesty and non-cooperation with treatment.

Averil also had a history of weight falsification. In Dr Christine Vize's report, she notes at Para. 107(b) that while an inpatient, Averil engaged in falsification techniques, and then readily admitted to it. However, she uses this admission to justify a finding that Averil did not falsify her weight as an outpatient. With other areas of dishonesty apparent from the medical record during Averil's time at NCEDS, this approach seems misguided. It is worth recalling that outpatients' falsification rate is almost double that found among inpatients.

[14] Jaffa et al (2011) *Improving Patient Weigh-ins,* 19 *Eur Eating Disord Rev,* p.368

We asked CPFT various questions relating to the manner in which Averil was weighed at NCEDS. While some questions were answered, others have not yielded a response. We do not know whether or not VP weighed her in outer clothes, or while wearing shoes, or if steps were taken to stop falsification.

We believe that the anticipation of falsification techniques, and the selection of appropriate weighing techniques to counteract them could have saved Averil.

Robinson (2009) notes that one patient falsified their weight through consumption of 10 litres of water. Although an extreme example, it demonstrates that water-loading can account for a significant difference between recorded weight and actual weight, and can explain the significant apparent drop between her weight recorded on the 23rd November, and her weight on admission to NNUH.

When Nic Hart visited Averil on the 28th November, Averil's physical state had deteriorated. He said that she "was in a worse condition than when she had been admitted [in 2011]." At this point, he estimated her BMI to be in the region of 11. **Figure 4** shows Averil's recorded weight throughout her time at NCEDS (black line) and an estimation of her real weight with consistent weight loss masked by her falsification efforts (blue line). On the 28th November (marked), her BMI would have been consistent with the observations made that day, and falsification techniques are still able to account for the difference in observed weight on the 23rd November, and Averil's projected weight with falsification.

Carol Miles, Averil's cleaner at university, also estimated her appearance to be similarly shocking. She raised her concerns with her supervisor, and reported them to the Hart family after Averil's death: "Averil was clearly very unwell, and in my opinion should be in hospital on a drip. She was hardly able to walk up the stairs." Such profound health concerns apparently went unnoticed by NCEDS.

Of the two alternatives proposed by Dr Vize in her report, we believe that the former is correct:

> *107(e)(ii): [Averil]'s weight was declining faster and further than the figures suggest. This alternative implies that she had been falsifying her weight, and either she was trying to disguise her appearance or the change in it had not been noticed.*

Dr Vize appears to believe this too, presuming that falsification techniques had occurred:

> *A crisis plan that included a BMI/weight at which readmission should be considered, would have been useful, but is unlikely to have altered the outcome, because of the discrepancy between the observed and actual weight.*

Had appropriate measures been taken to anticipate falsification techniques – and the care plan not changed to remove GP monitoring – Averil would not have been able to mislead her carers, and an informed decision about re-admission could have been made if her decline was noticed.

Physical Symptoms of Anorexia

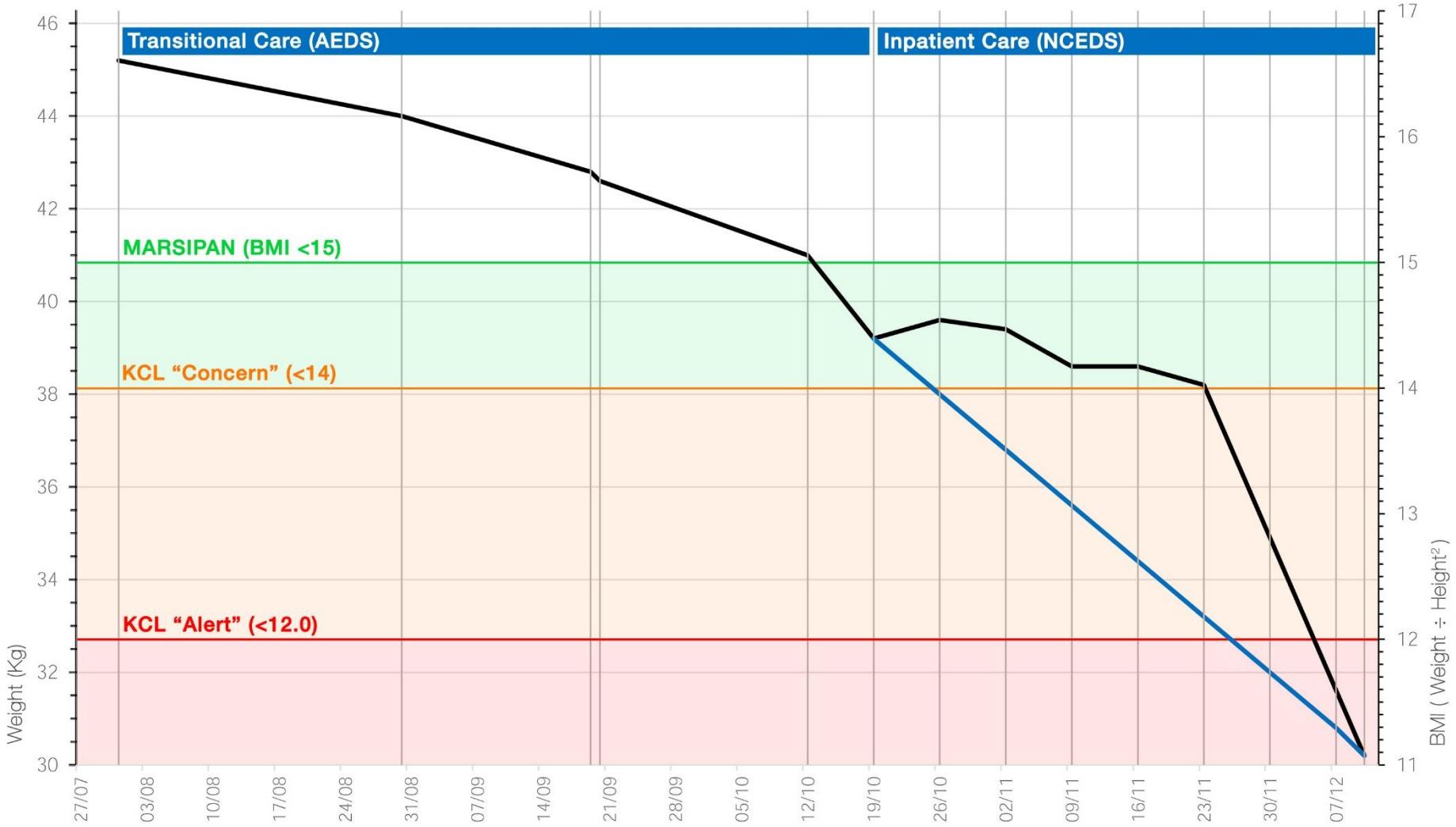
The draft service specification for the CEDS Service (16953) references several symptoms on the basis of which admission to hospital should be considered, including very low weight, BMI <15; rapid weight loss, marked medical complications, pronounced oedema, severe electrolyte disturbance or hypoglycaemia.

Of this list, oedema, rapid weight loss and very low BMI can only be determined through a careful physical examination of the patient, and the others would not be recognisable to a person without medical training. At all points, physiological monitoring of Anorexia patients is essential, as "neither BMI nor blood tests alone are adequate markers of risk" (Treasure, 2009).

We believe that VP's decision to assume monitoring of Averil's weight led to the cessation of monitoring by her GP, and that VP was unable to recognise these physical signs in Averil, as she lacked relevant medical or nursing training, and was ill equipped to assess physical risk.

Figure 4: Averil's Weight and BMI in Transition and at NCEDS

Averil's recorded weights **(black)** indicate that the MARSIPAN guidelines applied for the entirety of her inpatient care. If even weight loss with falsification (blue) had been noticed, points of concern and alert (under the King's College Guidelines) would have been reached at weekly psychological appointments.



3.8. Failure to Account for Anorexic Behaviours and Traits

There is significant evidence in Averil's medical file to show that she displayed over-optimism about her condition, and displayed evasive behaviours when her physical state worsened. In her CPA Care Plan at discharge, Jane Shapleske recognises her "difficulty to experience 'negative' emotions", and in Dr Vize's independent professional opinion, based on the entirety of her medical file, she observes:

> *The material written by A herself in the CPFT notes indicates that, even when she was coming to the end of her inpatient treatment and was at her least unwell, she did not have a realistic grasp of the overall picture, or true insight… With support and probing she can identify reasons for lack of progress, but she is not really able to change her approach to them in order to change the outcome.*

This is typical for sufferers of Anorexia Nervosa, and should have been anticipated by VP. It is central to the nature of the condition that patients will often not cooperate with treatment, and will often believe that they are well while others around them raise concerns about their condition. This can be seen in Averil's diary entries at University:

> Oct. 18th *I am scared about opening up and letting someone help me. I feel comfortable in this routine and I don't want to have to change it even though I need to.*
>
> Oct. 24th *I am not doing very well, if I kept like this I wouldn't be able to stay at university. I am sure I am fine, no-one else seems worried.*

There is a recognition of a need to change, but a clear separation of willingness to change. Averil was convinced that she was fine, and claimed that nobody else was worried, despite the concerns raised by VP in their first meeting.

3.9. Failure to Consider Effectiveness of Treatment Provided

In the absence of evidence to confirm that Averil was falsifying her weight, we argue that there is still sufficient evidence that Averil's psychologist should have been put on notice of the risk of sudden weight loss, as detailed in her crisis plan.

This issue has been considered by CPFT's chosen psychiatrist, Dr Vize, who concluded that:

> *"The rapidity of such a loss was unprecedented for A and could not have been predicted by her CPFT weight records up to that point."*

We asked CPFT whether S3 identified if the new Care Coordinator and RMO appreciated the high risk of relapse in Averil's case, and her prior history of rapid weight loss. Their response was as follows:

> *The risk information available from February 2011 to September 2011 identified that Averil lost weight to 30.4kg, suggesting gradual weight loss. There was no information available regarding rapid weight loss prior to her admission to S3… From our experience of Averil's care on S3, we had no reason to suspect that Averil might have falsified her weight.*
>
> *In accordance with King's College guidelines rapid weight loss was when a person loses 2kg per week. This did not apply to Averil.*

However, there is much in this response that is demonstrably untrue:

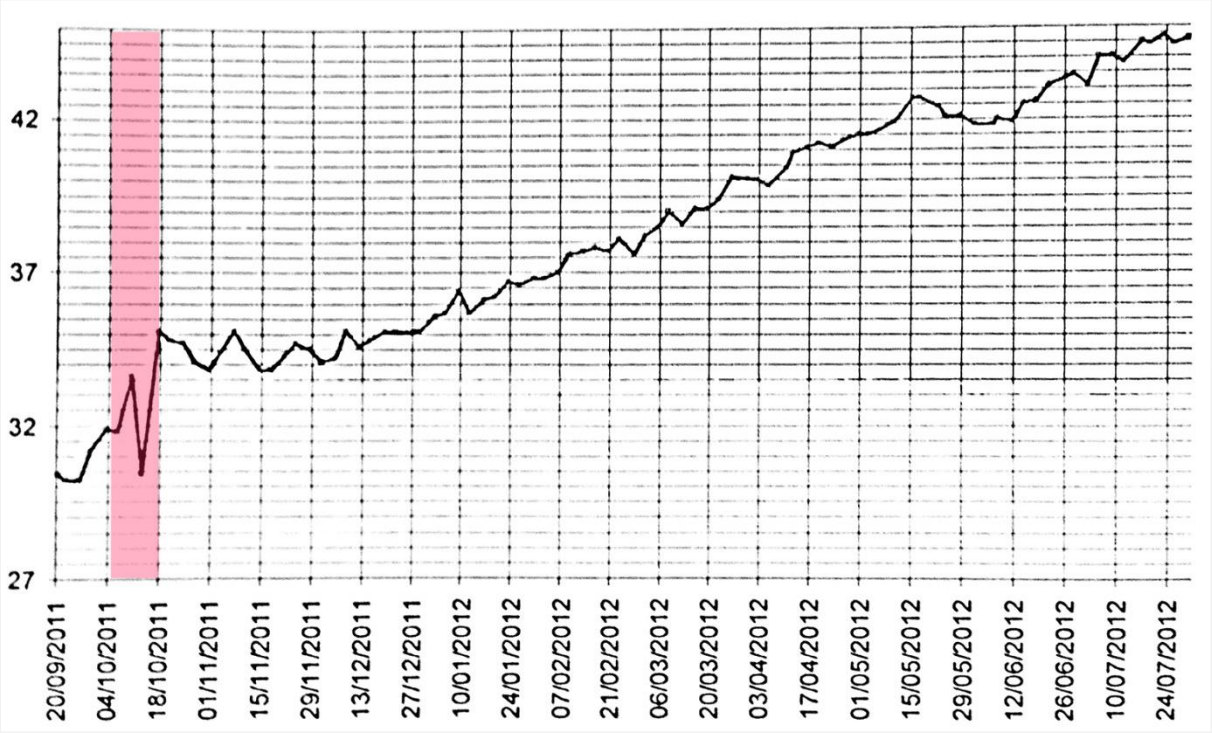
- Averil lost 3kg in the space of 1 week in October 2011, according to her S3 records.
- Dr Vize's report notes that at least one episode of weight falsification occurred as an inpatient, providing at least one reason to suspect falsification of weight.

- The King's College guidelines (Treasure, 2009) clearly state that rapid weight loss is at more than 1kg per week, see p.4. Concern is a rate of >0.5kg/week, and Alert is a rate of >1kg/week. The figures in the letter dated 17/01/2014 are incorrect.

Averil's overall weight loss from discharge (45.2kg on 2nd August) to VP's first appointment on October 19th (a period of 11 weeks), where she was measured at 39.2kg, was 6kg. This works out at an average rate of 0.5kg per week, significant enough to raise "concern", yet no action appears to have been taken on this basis. Instead, treatment continued as normal.

There is also clear evidence to show that a similarly rapid loss had already occurred, and was recorded in Averil's CPFT weight records. The graph below formed part of the Discharge Summary, indicating that from October 10th 2011 to October 14th 2011, Averil lost 3kg, even while she was under inpatient care. This evidence would have been available to VP and to all others caring for her (Figure 5).

Figure 5: Averil's Weight during Inpatient Treatment (September 2011 – July 2012)



The idea that this type of loss could not have been predicted is clearly false. There are indicators in her medical history of rapid weight loss, and throughout Averil's treatment at NCEDS, her care plan included reference to the fact that any weight loss could begin abruptly:

> *"Averil weight loss may be sudden and she may become frail and prone to falls."*
>
> CPA Care Plan updated at S3, 31/07/2012, 09:20am

In November, when VP updated Averil's care plan, she still stated that:

> *"Averil weight loss may be sudden and she may become frail and prone to falls."*
>
> CPA Care Plan updated by Vikki Powell, 22/11/2012, 09:00am

Averil's care co-ordinator was, therefore, aware of the risk of a sudden weight loss. In the light of this, we believe that her subsequent failures to arrange holiday cover, and GP health checks, for this period were inappropriate.

3.10. Failure to Plan for Absences, Creating Gaps in Treatment

We asked CPFT "Did the team have clear working arrangements for covering staff holidays / leave for high risk patients?" Aidan Thomas' response was as follows:

> *Clear arrangements were in place to cover staff absences. Specific cover arrangements for high-risk patients during periods of staff absences are discussed in team meetings and with the Consultant Clinical Psychologist during supervision.* (15th January 2014)

This does not explain why cover arrangements were not put in place in Averil's case. If it was normal to discuss cover arrangements in team meetings, why were they not discussed for Averil? VP had, in her document dated 13/11/2012, designated Averil as high risk, so why was this protocol omitted?

We believe that the failure to arrange holiday cover and medical monitoring for Averil meant that any opportunity to notice her rapid decline during this period was lost.

VP was, by the time she made her holiday arrangements, aware that Averil was at high risk. She also had awareness of the risk of sudden weight loss, and the knowledge that Averil would not be seen for fourteen days. However, no discussions were recorded in clinical supervisions, and no cover arrangements were made during this time period. Physical monitoring at UEA Medical Centre may have prevented rapid weight loss, or provided an opportunity for significant falsification to be recognised, while an appointment with a different psychologist, or VP's supervisor could have permitted a further judgment to be made on Averil's progress.

We have since asked several further questions of CPFT, which remain unanswered:

> **Questions:**
>
> - When did VP arrange her holiday?
> - Did VP make cover arrangements with reference to any patients at this time?
> - Were such arrangements discussed in clinical supervisions?
> - Why were internal protocols for arranging holiday cover not invoked in Averil's case?

Responsibility for such a failure, however, does not rest with VP herself, but with those who supervised her. It appears that supervision of Averil during her holiday was not discussed at any point, and CPFT has not confirmed whether or not arrangements were made for other patients. A new member of staff naturally requires more supervision and advice in these cases, yet it appears none was provided.

3.11. Failure to Raise Averil's Case at Weekly Meetings

The Serious Incident Inquiry Report prepared by CPFT notes that Averil was a high-risk patient, and that the failure to designate her as such meant that she was not discussed at the multidisciplinary team meetings that took place each week at NCEDS. The report states:

> *NCEDS… holds a list of service users that are reviewed within the weekly multidisciplinary team meeting and who are defined as 'high risk'. These include those with a BMI of below 15.00. […] In the case of AH – on referral to the NCEDS, AH's BMI was above 15.00 but at first appointment had dropped to BMI of 14.40. The investigation team was unable to clarify why AH was not placed on the 'high risk' list at this point and it appears to have been an oversight as AH's weight and BMI of 14.40 were recorded at the clinical supervision session of the 24 October 2012 with no resulting action taken to place AH on the 'high risk' list.*
>
> *This [telephone call] alert by AH's father appears to have also triggered AH's case being brought to the team meeting for discussion as 'high risk' on 4th December 2012.*

3.12. Failure to Accurately Record and Monitor BMI Data

The accurate recording of weight for Anorexia Nervosa patients is of paramount importance. A 2011 study by Tony Jaffa[15] noted that in inpatient settings, 30% of patients report weight falsification, but for outpatients, 57% are recorded as doing so. In light of this, training in how to measure the physical health of patients is essential.

We asked CPFT several questions relating to the training provided to VP and other NCEDS staff members at the time of Averil's treatment:

Questions:

- Was VP familiar with the physiological processes involved in weight loss?
- Did VP have specific training relating to the calculation and interpretation of patients' BMI data?
- Did VP have specific training relating to the analysis of weight trajectories and physical risk in relation to standard medical guidelines for the treatment and diagnosis of the various stages of anorexia? (E.g. King's College, MARSIPAN, NICE) If so, which?
- Did VP have practical experience of using the skills learned through this training?
- Did VP have training in other forms of medical monitoring or assessment of patients? This may include, but is not limited to blood pressure, SUSS Tests, or visual monitoring of physical health.
- In relation to these questions, did other members of the NCEDS team have such training or experience?

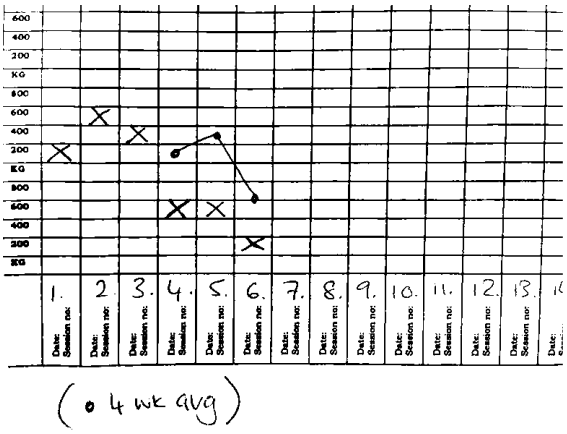
There is, additionally, no evidence to show the manner in which VP weighed Averil, and whether this was the same as the UEA Medical Centre method (yielding comparable results), or whether the method VP adopted accorded with common practice for the weighing of anorexic patients.

Even if measurements themselves accorded with recognised practice, the recording of those weight measurements suggested a lack of familiarity with both procedure and guidelines for anorexia patients. First, in most sessions VP recorded only Averil's weight, rather than calculating her BMI. Guidelines are prepared with reference to BMI, making weights less useful.

Secondly, the moving average calculated on the graph provided is incorrect at Session 5, where it should be 39.05kg. This created a falsely reassuring upward trend, rather than the downward trajectory that actually existed. The graph below is reproduced from VP's notes in Averil's file.

We believe that VP's failures to accurately record and assess Averil's weight are the result of a lack of suitable training and qualifications, which placed NCEDS' patient at a significant risk of physical decline.

VP did not appear to understand the meaning and the purpose of the King's College Guidelines in relation to the rate of weight loss observed.



[15] Which included the S3 Inpatient Unit, at which Averil was treated (See Jaffa et al (2011) *Improving Patient Weigh-ins,* 19 *Eur Eating Disord Rev,* p.368

3.13. Failure to Supervise the Trainee Psychologist

NCEDS, having made the decision to delegate Averil's care to an inexperienced member of staff, was under a duty as an organisation to provide proportionate supervision to counterbalance their delegate's lack of experience. **We argue that it failed to do so in an adequate manner, given VP's lack of knowledge about the importance of physical monitoring as well as other parameters of risk, as well as her lack of experience and training in doing so.**

Immediate Supervision

VP had weekly clinical supervisions with Madeleine Tatham, a consultant clinical psychologist. These weekly meetings, of which we have no record, are described in the CPFT Serious Incident Report:

> *Clinical supervision was provided on a weekly basis – on one occasion before VP's first session with AH and on 4 occasions during the course of her treatment. Clinical Supervision was not provided for 2 consecutive weeks for appropriate reasons i.e. annual leave and training.*
>
> 17 October 2012 – Clinical supervision Dr MT and VP – Care coordinator – discussion re AH – VP to contact Dr SB regarding transfer of case from AEDS. Supervision summary states – assumption this would involve CPA care plan, discussion regarding risk, summary of work undertaken and recommendation regarding further treatment.
>
> 24 October 2012 – Clinical supervision Dr MT and VP – AH's BMI identified and weight dropping from discharge to inpatient care noted. Aim to increase food intake and lower activity levels. To check AH going to GP for monitoring and weight to be done at NCEDS.
>
> 14 November 2012 – Clinical supervision Dr MT and VP – AH's BMI noted – Dr MT asked to see care plan and became aware there was not one updated since AH's discharge from S3. VP to progress drawing up a care plan.
>
> 21 November 2012 – Clinical supervision Dr MT and VP – no weight recorded in supervision notes as expected. States AH engaging with identified goals and therapy.
>
> 26 November 2012 – Clinical supervision Dr MT and VP – AH's BMI 14.00. Weight loss noted from second session to sixth session as being 1.4kgs. Care plan reported as being updated from previous inpatient care plan. Shared goals identified with AH as being to increase food intake and reduce exercise.

The content of these supervisions appears to have been limited. Despite the "discussion regarding risk", very little content appears to have been devoted to her overall condition. Each time, overall goals were stated as to increase food intake and to lower activity levels. Several points could have been raised in supervisions, but appear not to have been:

- CBT (even in its "enhanced" form) is widely considered not to be effective below a BMI of 15, and this was mentioned to the Hart family on Averil's admission to S3. It appears that neither MT nor VP considered this when deciding on the course of treatment, even under the "recommendation regarding further treatment" heading.
- Averil's Care Plan was supposedly discussed before Averil arrived, but on 14th November, it became clear that no new care plan had been drawn up. The issue of a care plan should have been raised earlier.
- VP wrote to UEA Medical Centre, assuming responsibility for weighing Averil. We see no evidence to suggest that she asked MT about this in advance, but simply informed that it had been done. MT appears to have raised no concerns with this, despite the fact that it resulted in a significant decrease in Averil's monitoring.

- As has been detailed above, there appears to have been no discussion of cover arrangements during VP's period of absence at the end of November 2012.

We have submitted the following questions to CPFT, but are yet to receive a response:

> It is widely known that BMI is a significant factor in the effectiveness of CBT, even in its "enhanced" form, and that it is often stated to be ineffective below a BMI of 15 (Fairburn, 2008). **Did VP consider, at any stage, the effectiveness of CBT in Averil's case, given her recorded BMI, which was below 15 in all six CBT sessions?**
>
> Averil lost 3kg between September 25th and October 19th, placing her into the "Alert" category in the King's College Guidelines. Why did VP or a supervisor not consider this to be a sign of alert? Why did they not take any action?
>
> Apart from initial instructions to UEAMC by NCEDS / S3, what co-ordination did VP's supervisor undertake to liaise with the UEAMC to check Averil's physical condition, bloods and other medical parameters?

We believe that insufficient action was taken to remedy the appointment of an employee who NCEDS knew was lacking in practical experience of treating patients with Anorexia Nervosa, especially during that employee's introductory phase at the service.

In addition to this, it was not clear who the Responsible Medical Officer was in Averil's case. This meant that there was no direct line of accountability for Averil's physical wellbeing.

Supervision at Higher Levels

There is no evidence of the involvement of those at higher levels within NCEDS on the face of the medical file before the emergency call on 28th November 2012. After this date, a few emails provide the only record of any contact with higher levels of supervision.

We believe that further monitoring and careful supervision should have taken place to ensure that their newly qualified staff member was adequately supported.

> **Evidential Difficulties and Outstanding Questions:**
>
> Although team meetings are mentioned once in the SI Report, we do not have any evidence to suggest that Averil's case was discussed at them, or that VP had any support from higher levels within the organisational structure.
>
> - Did VP have conversations with Dr JSh about Averil's case?
> - Did VP have conversations with Dr JSe about Averil's case?
>
> If so, in either of these cases, what did they involve?

3.14. Insufficient Crisis Management and Emergency Responses

On 28th November 2012, Nic Hart made an **emergency** call to S3 Ward, Addenbrooke's, as this was the only contact number he had within CPFT's Eating Disorder teams. The next day, he received a telephone call from Carol Downe, who reassured him that the NCEDS team was much better than its predecessor, and who informed him that immediate and effective action would be undertaken; good care would be taken of Averil. No record remains of these phone calls.

In response to this clear indicator of a threat to Averil's safety, Jaco Serfontein e-mailed VP and Louise Brabbins the next day (30th November):

> *Averil Hart's father visited her yesterday. He has not seen her in a month and was very concerned by her weight loss. He phoned the ward three times yesterday. I think she needs a medical review. Louise, could you arrange to see her, please? With Vikki, if possible.*

The result of this call was to arrange a medical review ten days later, on 7th December. By this point it was too late. We believe that this delay was the result of a lack of clear procedures and judgment for how to deal with external information, and how to react to concerns about patient safety.

The Serious Incident Report commissioned by CPFT explained that such a review would not have happened without external intervention:

> *However the investigation team could not confirm that such a review would have been requested at this point had it not been for Mr H's alert.*

In other words, the NCEDS team was not aware of Averil's dangerous condition.

Failure to Respond to an Emergency Situation

The response provided to the emergency call made on the 27th November was insufficient, the long delay between alert and review contributing to Averil's significant decline over the ten day gap. We believe that this was due to a failure to establish procedures for reviewing patients when concerns were raised.

Having asked CPFT why the response to the emergency call (medical review) was not quicker, we received the following response:

> *Based on the risk information available to Dr Serfontein as described above in point 17 that indicated a gradual decline in weight, no history of rapid weight loss or falsification of weight and that Averil was engaging in her treatment with her Therapist, the review was classified as a priority but not urgent. The review meeting arranged for the 7th December 2012 was considered to be an appropriate timeframe.*

However, this fails to take into account that more relevant information had been provided since the weight records were prepared. Carol Downe had communicated the nature of Nic Hart's message to S3 ward, noting the extent to which Averil's father believed her appearance to have deteriorated. Dr Serfontein mentioned the concerns about weight loss in his e-mail to VP and Louise Brabbins. This was relevant information, it indicated significant weight loss, which would not have been explained by the previous month's weight records.

Failure to Establish Emergency Procedures

The response of the NCEDS team shows a complete lack of emergency procedures, which compromised the safety of their patient.

The chaos within the service is clearly visible from the e-mail trail produced after the team were informed that Averil had been admitted to Norfolk and Norwich Hospital. The team discusses Averil's admission, about which they have a lack of information, but immediately decide to "find out what the situation is" the following Monday. With several "service hours" left on Friday afternoon, a visit could have been made by a member of the team. This did not occur until the 10th December.

4. North Norfolk CCG – Failure to Supervise NCEDS

North Norfolk Clinical Commissioning Group pays approximately £850,000 to NCEDS each year for their provision of treatment for eating disorders. It would be expected that such expenditure would be safeguarded through monitoring of the treatment commissioned. However, this appears not to have been the case. **We believe that NNCCG is failing its patients by not performing adequate quality controls to ensure that the care commissioned complies with the service specification, and that modifications are made when it fails to meet the required standard.**

In a meeting on the 17th May 2013, we discussed this issue with NNCCG, and discovered that no checks were made either by current staff, or by their predecessor, Norfolk and Waveney Foundation Trust, in the following categories:

- No checks were made to ensure that CPFT's service was being provided in accordance with the contract agreed upon. The service specification reveals numerous performance targets and monitoring checks for patients, which are not being adhered to. Breaches of these terms are going undetected by NNCCG.
- No checks were made to ensure that high risk patients were receiving satisfactory ongoing care and regular reviews of their care plans and risk assessments.
- No checks were made to verify that the services provided were being properly funded and resourced by CPFT. The head of NCEDS stated that issues with under-resourcing of the unit continued throughout Averil's treatment, and we believe they remain problematic today.
- No checks were made to ensure that the service provided by CPFT was following the NICE Guidelines, with which compliance is demanded by the service specification, and the MARSIPAN guidelines, which represent best practice for eating disorder treatment.
- No checks were made to ensure that the service provided by CPFT / NCEDS had proper "emergency procedures" in place to care for high risk patients.
- No checks were made to ensure that NCEDS had the ability to liaise with hospital acute wards in out-of-hours situations, in order to provide vital information about patients to physicians treating Eating Disorder patients. It appears no attempts had been made to mention such provision during commissioning.
- No checks were made to ensure that NCEDS had systems in place to communicate both routine and emergency matters with patients' families.
- No routine checks were made to ensure that patients and their families were satisfied with the service and safety of the service provided by NCEDS.
- No sanctions appear to have been put in place to penalise poor performance or outcomes, or to require changes be made when adverse outcomes arise.

It also appears that NNCCG had a severe lack of basic knowledge about the service. Key members of the North Norfolk team suggested at an initial meeting that they thought NCEDS was a charity. We consider this to be unacceptable, especially as nearly £1m of tax-payer's money is spent each year, and NCEDS remains responsible for the safety and wellbeing of the patients that the CCG is supposed to represent within the NHS.

5. Primary Care: UEA Medical Centre

Averil's care at UEA Medical Centre proceeded on the basis that weighing and monitoring a patient with Anorexia Nervosa was a Primary Care responsibility. Doctors at the Centre had already undertaken specific training concerning eating disorders, as provided by BEAT, an eating disorder charity, and should have been aware of the specific risks of anorexia, and best practice in its treatment.

We believe that UEA Medical Centre failed to follow the instructions communicated to them by Averil's care co-ordinators, and failed to notice physical symptoms that would have identified the significant deterioration in Averil's condition. Without sufficient primary care contact, Averil's rapid decline went unnoticed by the only medical professionals in a position to observe it.

Averil registered at UEA Medical Centre on the 27th September 2012. Sarah Beglin, Averil's care co-ordinator at S3, telephoned ahead to inform them that she would be registering and that she was at significant risk, and to make several requests of them. The notes from this telephone call read:

> *Her BMI is now 15, has been a lot worse, she is still regarded as fragile, new start at Uni could be potentially dangerous time for her… Averil has lost some weight since her discharge, she has been out a few weeks and is vulnerable at the moment. […]*
>
> *4, Dr Beglin would like the safety net of medical centre and hopefully a named GP for her. If any uncertainty or things slip with this patient then please contact Dr Beglin for advice…*

These requests were followed by clear instructions in the letter sent to them on Averil's discharge:

> *GP: Please check Averil's physical health every week (weight, BP, heart rate and level of physical strength – Squat test). This can be done by a nurse. Please monitor her bloods every 2 to 3 months including U&Es, bicarbonate, LFTs, bone profile, muscle CK, Magnesium and Phosphate.*

We believe that they failed to meet these requests, and heed her warning about risk. These specific claims were raised in the complaint originally submitted to NHS England, but are re-iterated here.

5.1. Failure to Provide a Named GP

Dr Beglin requested a named GP for Averil in order that she had a continuing point of contact for her Primary Care. Her "Usual GP", according to her medical records, was Dr Suzanne Edmonds. Averil was not seen once by Dr Edmonds, who has since confirmed that she had no involvement in her care.

Averil was seen by four separate staff members between the 29th of September and the 8th November:

- 29th September 2012 – **Mr. Oliver Tyrrell,** weight 42.2kg, no other tests completed.
- 5th October 2012 – **Mrs. Paula Winter,** weight 42kg, blood pressure 103/67mmHg.
- 12th October 2012 – **Dr Matthew Green**, weight 41kg, no other tests completed.
- 25th October 2012 – **Dr Wendy Clark,** weight 41kg, blood pressure 95/65mmHg, HR 55 reg., no problems reported with squat test.
- 8th November 2012 – **Dr Wendy Clark,** weight not recorded, HR 55 reg. "Review in a month".

By failing to provide a named GP, the UEA Medical Centre deprived Averil of the benefit of continual monitoring by the same individual. This was particularly damaging for her, as it meant that physical changes could not be observed, and she could not build up the type of collaborative relationship that can assist in recovery from anorexia.

5.2. Failure to Carry out Tests as Requested

However, of the weekly tests requested, and the bi-monthly blood tests, the following table establishes the number of tests ordered and the number of tests actually carried out. The weekly tests were:

	1	2	3	4
Weekly:	Weight	Blood Pressure	Heart Rate	SUSS Test

The bi-monthly blood tests were:

5	6	7	8	9	10	11
U&E's	LFT's	Bicarbonate	Bone profile	Muscle CK	Magnesium	Phosphate

However, it appears that the full range of weekly tests was completed only once, while the bi-monthly blood tests were never completed at all. Column 12 also indicates ECGs, as required under the King's College Guidelines. The full record of when these tests were completed is as follows:

Cal. Week	1	2	3	4	5	6	7	8	9	10	11	12
24/09	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
01/10	✓	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
08/10	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
15/10	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
22/10	✓	✓	✓	✓	✗	✗	✗	✗	✗	✗	✗	✗
29/10	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
05/11	✗	✗	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗
12/11	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
19/11	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
26/11	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
03/12	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
07/12	*Averil found unconscious in her flat at University.*											

This table demonstrates the failure of the UEA Medical Centre to follow the instructions that were given to them in Averil's discharge summary. No blood tests were taken at any point.

When Vikki Powell wrote to UEA Medical Centre on 26th October 2012, she stated:

> *Given your BMI it is important to continue the regular medical monitoring with your GP. You did raise concern about the weekly discrepancies between the scales at your surgery and the NCEDS clinic… I would suggest that whilst regular monitoring of your BP is important to continue, these GP visits do not need to include taking your weight.*

This letter is, undoubtedly, unclear in its instructions to the GP. It is likely that it was intended to require all tests to continue on a weekly basis, except weight. It is clear from the table above that this was not the interpretation reached by UEA Medical Centre. However, even the most restrictive reading of this request requires Averil's GP to monitor Blood Pressure on a regular basis. After the 26th October, not a single reading was taken. The Medical Centre failed to follow even this most minimal of instructions.

Finally, the Medical Centre failed to follow its own instructions. On 12th October, a note on Averil's file, made by Dr Matthew Green, states:

> *Plan to check bloods, do forms next week.*

Averil was unable to make an appointment on the 19th due to her appointment at NCEDS, which she explained in an e-mail (below). However, the notes from this last appointment would have been available to Dr Clark, who took her appointment on the 25th October, yet she made no arrangements for blood tests. No reason has been given for this failure.

In an attempt to justify this conduct, Dr Edmonds has written (letter dated 23rd May 2013) to explain that Averil's instructions were responsible for changes in care:

> *We did receive an e-mail from Averil on the 20/10/12, in which she confirmed that she was under the Norwich Eating Disorder Team and that she would be attending weekly therapy and weighing at that service. The tone of that e-mail was very positive. [Her steady weight and her reports of feeling positive] led the clinicians up until early November to believe that there were no immediate serious concerns.*

The relevant e-mail reads as follows:

> *Yesterday, Friday 19th, I attended my first appointment with the Norwich Eating Disorder team who will be taking over my care whilst I'm at university and arranged a weekly CBT session as well as weight monitoring. It was a very positive first visit and I feel they will be able to offer me a lot of support and everything that I need to move forward and keep progressing well at University. I thought that you would like to be kept up to date as I was unable to make an appointment with you yesterday afternoon as a result – I have re-arranged this for the next available slot which is next week.*

UEA Medical Centre here betrays its naïve attitude to sufferers of anorexia nervosa. An e-mail from a mentally ill patient regarding their own health should not be taken at face value, especially in guiding treatment/monitoring.

Anorexia Nervosa is an ego-syntonic disorder, encouraging conduct and communications that are inconsistent with the aim of recovery, and which favour the patient's body ideal over physical safety. An anorexic patient that states that a service offers "everything that I need" cannot be trusted. Moreover, any such communication would have been superseded by VP's instructions dated October 26th 2012, which asked that Averil's physical monitoring continue regularly, reiterating the need for monitoring of non-weight factors. Averil's earlier e-mail should not have been given precedence over VP's instructions.

Failure to Question the Premise of the Instructions Given

The justification for the change in medical monitoring arrangements made by VP was a discrepancy between the weight measurements taken at UEA Medical Centre and at NCEDS. At the very least, this discrepancy was 1.8kg, the difference between 41kg and 39.2kg. This, however, represents a significant percentage of body weight for such an underweight patient. More detail would, of course, allow for an assessment of whether or not it was possible:

- Does UEA Medical Centre calibrate its scales regularly?
- Does UEA Medical Centre have procedures for weighing patients accurately?
- How was Averil weighed? Was she weighed with clothes and shoes, or without them?

We believe that it is inconceivable that such a difference could have existed. It is more likely that the difference was due to differences in the manner in which weighing was carried out. Neither NCEDS

nor UEA Medical Centre has confirmed this, and neither has explained how weights were recorded, and therefore we cannot determine exactly where the difference lay.

Failure to Account for Weight Falsification

Our only point of evidence as to how weights were recorded at UEA is based on Averil's own account of her appointment there on the 5th October, when she was recorded as weighing 42kg:

> 4th Oct: *Feel scared about my weigh in...I know that I've gone down. I am scared of changing my 'safe' routine.*
>
> 5th Oct: *I am surprised I didn't lose more weight – 42 kg. I know it is different scales and lots of layers and not peeing.*

This both reveals that Averil was weighed while wearing significant quantities of clothing and having "water loaded", and that she knew she had lost significant amounts of weight, even if they were not indicated by the measurement itself.

UEA Medical Centre should have been aware of the risk of weight falsification in Anorexia Nervosa, as this affects 57% of outpatients (Jaffa, 2011), and is widely known, even beyond medical circles. This is also mentioned in the King's College Guidelines, as "potential for deceit." There was no clear protocol for weighing patients, and the doctors who saw Averil failed to account for this risk in the manner in which they weighed her.

5.3. Failure to Follow King's College Guidelines

The King's College Guidelines were issued to UEA Medical Centre by Dr Beglin on the 27th September 2012. She said they would be grateful for the centre's "medical monitoring" of their patient. **We believe that the UEA Medical Centre did not follow the Guidelines of which they had a copy, and which they had been asked to consider.** The King's College Guidelines suggest:

> *We recommend the following for a rapid risk assessment, repeated frequently as necessary*
>
> - *BMI*
> - *Blood pressure and pulse rate, lying and standing*
> - *Muscle Strength*
> - *Examination of the skin and temperature for those at high risk for dryness*
> - *A full physical examination looking for e.g. infection (note can be with normal temperature) and signs of nutritional deficiency.*

These tests are not exhaustive, and the guidelines explain:

> *Neither BMI nor blood tests alone are adequate markers of risk. Screening for risk with an examination of muscle strength, blood pressure, pulse rate, peripheral circulation and core temperature is essential.*

UEA Medical Centre, despite being told to care for Averil with reference to the guidelines, did not do so. They did not carry out the tests stated to be ***essential***. We can see clearly that Averil's condition was declining throughout the relevant time period, and a full physical examination should have been carried out on at least one occasion. The importance of this will be explained at **5.4** (below).

Moreover, the Centre failed to carry out its blood pressure checks in accordance with the guidelines, which state "lying and standing" in order to detect postural hypotension, which is a key indicator of muscle weakness as a result of anorexia nervosa.

5.4. Failure to Observe Physical Symptoms

Averil's diary reveals evidence of physical symptoms which may have masked weight loss, and which indicated the extent of the decline in her condition. We believe that UEA Medical Centre should have been aware of these physical symptoms and should have noticed her physical signs during the course of the physical examinations they carried out up to the 8th November.

> 14th Oct: Averil mentions *"swelling in my ankles"*
>
> 15th Oct: *It is getting harder to walk upstairs, and oedema in my legs is getting worse.*
>
> 24th Oct: *Chest really hurts and my ankles are so swollen.*
>
> 28th Oct: *Fell – fluid by my knees.*
>
> 16th Nov: *Knees really sore and fluidy.*

Here, Averil identifies two significant symptoms of severe anorexia nervosa – peripheral oedema and swollen joints – both of which are symptomatic of poor recovery for a patient with severe anorexia nervosa. Oedema is of special importance because it can conceal the extent to which weight has been lost, as water gathers either within or between cells, adding to body mass without providing the benefits of weight gain.

> *There are five different possible mechanisms for peripheral oedema: 1) hypoproteinemia, 2) electrolyte imbalance, 3) hormonal changes, 4) rapid refeeding, 5) sudden discontinuation of laxatives, diuretics or diet pills.*[16]

In Averil's case, there was no evidence of rapid refeeding, as Averil was losing, not gaining weight, and there was no history of use of laxatives, diuretics or diet pills, so these are unlikely to have contributed to the presentation of such symptoms.

The other three mechanisms all require blood tests for an accurate diagnosis. Such blood tests were requested by those discharging her from S3 Ward, yet were **never** carried out by UEA Medical Centre. However, they should also have noted physical symptoms and signs on examination, which presented while the Centre had regular, weekly contact with Averil. Had they been noticed, blood tests could, and should, have been ordered to determine the cause. Had they not have been noticed, the cause (hypoproteinemia, hormonal change, or electrolyte imbalance) would have been more likely to have been picked up by the blood tests requested.

On 4th October, Averil's diary mentions another physical symptom that could have been noticed by a GP carrying out a physical inspection:

> *Belly hurts and I am bloated. Swollen glands.*

Sub-mandibular enlargement is cited as a symptom of severe anorexia nervosa, caused by the malnutrition associated with the illness.[17] As has been observed elsewhere, they *"might be the only visible sign for the disease."*[18] Gland enlargement could be detected by a physical examination, especially if it was already apparent to the patient.

We believe that the failure to observe these physical signs relevant to a condition so prominent in Averil's history meant that opportunities to prevent her physical decline went unnoticed.

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[16] Derman, O., Zinnur Kılıç, E. (2009) *Edema can be a handicap in treatment of anorexia nervosa.* 51 Turkish Journal of Paediatrics, pp. 593-597

[17] Walsh *et al.* (1981) *Anorexia Nervosa and Salivary Gland Enlargement.* 11 Int J Psychiatry Med (3) pp. 255-261

[18] Bozatto *et al.* (2008) *Salivary gland biometry in female patients with eating disorders.* 265 Eur Arch Otorhinolaryngol (9) pp.1095-1102

6. Norwich and Norfolk University Hospital

Averil was taken to Norwich and Norfolk University Hospital by ambulance after being found unconscious, collapsed in her flat. She arrived at 12:15 on 7th December. Three minutes later, she was seen by a nurse, and 20 minutes later, by a doctor. She had low blood pressure, hypothermia, hypoglycaemia and dehydration. Her blood sugar level collapsed to 1.1 shortly after, whereupon she eventually permitted the use of a 5% glucose infusion. Over the next three days, Averil suffered a fall, and her physical condition declined significantly. During this time, she was not assessed by a psychiatrist.

6.1. Failure to Provide Appropriate Specialist Attention

Averil's case was managed by Dr Jamieson, a Gastroenterology consultant, who assessed Averil at 18:15 on the day she was admitted. He made a similar assessment to the consultant who reviewed Averil earlier in the day as having liver dysfunction, with possible impaired renal function. The suspicion was a paracetamol overdose. However, the staff involved were aware of Averil's history of Anorexia, but failed both to provide appropriate care, and to provide appropriate psychiatric contact.

Failure to Engage Psychiatric Liaison Services

Anorexia Nervosa can require emergency physical treatment, as became apparent when Averil was admitted to hospital. However, it also requires emergency psychiatric assessment in addition to the acute physical treatment that severe weight loss requires to be corrected. This should include an assessment of the patient's capacity to consent to treatment and consideration of detention under the Mental Health Act 1983 to allow urgent physical treatment to be given if consent is withheld. This would have been evident from Averil's medical history alone.

From her admission on Friday 7th December to her visit from NCEDS on Monday 10th December, Averil received no form of psychiatric assessment or contact. There is a Psychiatric Liaison Team based at NNUH, but they appear to have been unavailable during this time.

6.2. Failure to Provide Anorexia-appropriate Care

There can be no doubt that the gastroenterology team at NNUH was equipped to deal with Averil's acute liver failure, as Dr Forbes concluded:

> *The striking abnormalities in this patient's case had more to do with evolving acute liver failure than simply with anorexia nervosa. This was addressed very appropriately and it is difficult to see what more had been done.*

However, it appears that no tests were carried out to determine whether paracetamol poisoning had actually caused the liver failure, or whether it was a consequence of Anorexia Nervosa itself. The conclusion was reached based on Averil's explanation that she had been taking a strong flu remedy for "fresher's flu", but had stopped almost a week earlier. On the morning of Averil's transfer to Addenbrooke's, Averil's medical notes apparently stated:

> *Results of all liver aetiology tests all negative/normal.*

It is suggested by Dr Tony Jaffa – who prepared the Serious Incident Report for CPFT – that Averil's condition was caused by Anorexia Nervosa, rather than by Paracetamol poisoning:

> *Her blood and liver function results at the N&N were consistent with severe malnutrition due to Anorexia Nervosa and, as far as the investigation team are aware, did not show high Paracetamol levels.*

Averil's Anorexia Nervosa remained relevant to her condition and to her treatment throughout her time at N&N. In light of this, the failure to provide treatment in accordance with the MARSIPAN guidelines, which relate directly to the treatment of Anorexia Nervosa in acute hospital wards, was a significant contributor to the decline in Averil's condition.

Failure to prevent Physical Activity

Severely ill patients with Anorexia Nervosa require their movement to be limited as much as possible, this avoids any damage to their recovery, and minimises the risk of falls or other damage. The MARSIPAN guidelines warn of the use of exercise in the pursuit of thinness, even while in hospital:

> *Patients… may engage in obsessive exercise such as running up and down hospital towers (following notices often displayed on hospital stairs encouraging exercise to promote health), standing, wiggling toes and generally walking around...*

However, it is essential that such activity is minimised, and inpatient units attempt to achieve this by requiring wheelchairs to be used, and supervising all movement. In a hospital ward, this may be less practical, but permitting a patient so close to collapse to walk around the ward unsupervised and unchaperoned was irresponsible.

Averil suffered a fall and a head injury as a result of being permitted to move around the ward, and it appears that the risk of this happening was not taken into account by those treating her at NNUH.

Failure to provide appropriate feeding protocol

During her time at NNUH, Averil was required to feed herself from a trolley. In a letter from NNUH responding to our original complaint, it was stated that this was the result of a decision with Dr Serfontein. We do not believe that this can have been the case.

Averil had, within her first few hours at NNUH, begun to refuse treatment. She rejected a glucose infusion (while her blood sugar was 2.1) and treatment for hypothermia. While she subsequently agreed to an infusion, the earlier refusal of simple glucose (which took place before the purported discussion with Dr Serfontein), is a clear sign that Averil's capacity to choose nutrition had been subsumed by the psychological urge driven by her condition. In light of this, the decision to permit Averil to feed herself over the weekend, rather than to engage nasogastric feeding, was inappropriate and was a major factor endangering Averil's chances of survival.

7. Addenbrooke's Hospital

When Averil was transferred to Addenbrooke's Hospital, we hoped that they would be able to provide the care that would save her. They were our last hope: we knew that they had high quality wards that could provide specialist care, and could liaise with one another to ensure that eating disorder-specific considerations guided her care. This was not the experience we received.

7.1. Significant Delays in Admission to N2 Ward

Averil arrived at Addenbrooke's at 14:40 on 11th December 2012. She had a BMI of approximately 11.4, and was still suffering from complications relating to paracetamol poisoning. The letter referring her care to Addenbrooke's stated:

> *In the light of Averil's rapidly deteriorating health, medical instability and inability to make positive changes in the community the initial goal will be to manage her medical risk as an inpatient. She will need carefully monitored refeeding to avoid refeeding syndrome or further weight loss. This process requires specialist nursing, medical and psychiatric care.*

Her admission to the N2 gastric ward was carried out by the night Senior House Officer (SHO) at around 8pm that night, nearly six hours later. At this time, Dr Serfontein, along with Dr W and LH, the dietician on the ward, reviewed Averil's case. Dr W requested blood tests to be taken and for oral glucose to be given if her blood sugar fell to 3.0 or below.

No explanation has been given for the significant delay in admission, and it has been acknowledged that earlier blood tests would have improved the Consultant review Averil received.

7.2. Failure to Make a Full Assessment of Capacity

Before Averil was admitted to N2 Ward, it had been stated that the purpose of the transfer was to engage Nasogastric feeding, and that sectioning under the Mental Health Acts would be required in order to do so. This never occurred, and Averil continued to refuse treatment until the morning of the 12th December, whereupon she became unconscious.

Had a full psychiatric assessment of capacity been carried out on admission, consideration of detention under the Mental Health Act 1983 could have been obtained to enable medical treatment to be given without Averil's direct consent.

Despite our complaint about the delay in seeking psychiatric assessment and consideration of detention under the Mental Health Act 1983, no specific detail has been given as to how this was dealt with. Through her time at NNUH, Averil either accepted or rejected treatment at different times, and although she agreed to nasogastric feeding on admission, an assessment would have been appropriate in light of the previous days' records.

7.3. Failure to Assign Appropriate Staff to Averil's Care

Averil was accompanied overnight by a Mental Healthcare Assistant, who lacked nursing experience. As a result of this, Averil's condition, which declined rapidly overnight, went unnoticed. When Dr Woodward reviewed her the next morning, Averil was unresponsive and displayed poor respiratory effort, and a crash call was made immediately.

No explanation has been given for this delegation of monitoring responsibilities.

We asked Aidan Thomas why a bank Nurse was allocated to Averil, when they clearly had no experience or training in working with people with Anorexia Nervosa. Although we now know that the MCA had no nursing experience, the purpose for which delegation was made remains relevant to assessing their suitability to the role. His response was as follows:

> *The bank staff was there to support Averil to minimise the amount of standing and exercise. This in itself is not complex.*

Averil, who is described as being "extremely weak, unable to even lift her head from the pillow," is unlikely to have engaged in any "standing" or "exercise." During her time at Addenbrooke's. The purpose of 1:1 supervision was to observe Averil's condition, a function which this MCA could never have adequately performed.

7.4. Failure to Communicate Adequately

The Serious Incident Report prepared by Addenbrooke's Hospital discusses failures in communication between Dr W and Dr T. These were significant in affecting the care provided overnight, but there is little complexity to the issues raised.

8. Inter-Agency Communication

As an illness that has both profound physical effects and significant mental impact, Anorexia Nervosa requires particularly specialised treatment.

8.1. Lack of Communication between NCEDS and UEA

Neither UEA Medical Centre nor NCEDS communicated appropriately as regards Averil's care when compared to the standards set out in professional guidelines. The MARSIPAN Guidelines state:

> *By the nature of their illness, MARSIPAN patients require care from various professionals and regular multidisciplinary review is vital to coordinate this care.*

The emphasis of these guidelines is that communication between primary and secondary care is essential to the overall management of patients with Anorexia Nervosa. However, it appears no multi-disciplinary review took place. The following communications were made between NCEDS and UEA:

- 27th September – Sarah Beglin calls Kevin Burgess to request Averil's ongoing care, sends a letter to Dr Edmonds to enclose King's College Guidelines.
- 23rd October – Dr Green at UEA writes to Averil's disability coordinator to ask for a fridge.
- 26th October – VP writes to Averil to confirm the start of her treatment, and that she will be weighed at NCEDS, not UEA Medical Centre.

During this time, there is no sign of "regular multidisciplinary review", and no communication between Averil's primary and secondary carers. We asked CPFT:

> *Having spent ten months caring for Averil and arranging a hand-over to NCEDS and UEA medical centre, what follow up was undertaken to ensure that these agencies had received, understood and importantly, that they would undertake the instructions imparted in the discharge care plan?*

And received the following response:

> *The letter from Dr Beglin to Averil's GP dated 27th September 2012 outlined responsibility and a copy of the King's College Guidelines and discharge summary which contained the frequency and detail of the monitoring dated 3rd August 2012 was included. As outlined in an earlier point in this letter, the therapist sent a letter to Averil's GP on 26th October 2012, to remind them of the necessity for medical monitoring. The therapist was undertaking Averil's weighing instead of the GP and Averil's weight was monitored during her active treatment.*

This fails to answer our question. The purpose of inter-agency communication is a *dialogue* which can clarify that instructions have been received, and will be accurately carried out. Although NCEDS sent information to UEA Medical Centre, UEA failed to reply, or to seek clarification, and NCEDS simply assumed that that these instructions had been received and that the work was being undertaken. Such a laissez-faire attitude is unacceptable.

8.2. Failure to Verify Results of Medical Examinations

It appears that VP's knowledge of Averil's test results at UEA Medical Centre was entirely based on Averil's communication of their results to her. She had made no attempt to contact Averil's GP to obtain any test results, or to check that the tests were being carried out at all. This was also true of the transitional period between S3 and NCEDS care.

We questioned why such monitoring was not carried out during the transitional care arrangements, and have since received a response from CPFT:

> *See 2.0 above. [2.0 references attached document] Clear instruction was provided to Averil's GP on 27 September 2012 regarding her treatment requirements.*

This does not answer the issue raised. Our complaint referred to steps taken to verify with the primary care team that the weekly requested checks were being carried out, and to verify their results. This response details the instructions given that requested those tests. The two are separate matters.

We believe that the failure of NCEDS to check that tests were being carried out, and to check their results, was a cause of Averil's physical deterioration, which led to her death. Psychological treatment then continued with insufficient empirical medical data to inform the decisions made.

8.3. Lack of Communication between NNUH and NCEDS

When Averil was admitted to NNUH, her mother telephoned NCEDS to inform them that she had been taken to hospital. However, when NCEDS contacted the ward, they were unable to obtain sufficient information to provide specialist advice.

This matter has been extensively discussed in prior complaints, but the extent to which the matter has been dealt with will require follow-up with the organisations involved in the light of Dr Vize's recommendations, and those of the Serious Incident Report prepared by CPFT.

Concerns Regarding the Complaints Process

9. Cambridgeshire & Peterborough NHS Foundation Trust and North Norfolk Clinical Commissioning Group

Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) and North Norfolk Clinical Commissioning Group (NNCCG) agreed that the investigation would be led by the North Norfolk team. However, due to the nature of our inquiries, and requests by both organisations, we have dealt with both CPFT and NNCCG, and the majority of our complaints relate to CPFT.

9.1. Failure to Acknowledge Mistakes

Averil left for University in September 2012, yet by the 15th December, she died of a treatable illness, while ostensibly under the care of two separate organisations. CPFT, which runs one of them, is yet to acknowledge that any mistakes were made in Averil's treatment. Following Averil's death, we received several letters which expressed sympathy for our loss, including one from Caroline Nightingale:

> *On behalf of myself and the team, I am writing to offer our heartfelt condolences on the sudden death of Averil.*

One year after Averil's death, on 20th December 2013, we also received a response from Dr Shapleske, who expressed her condolences, but despite her responsibility for both teams that supervised Averil, she has made no attempt to explain that mistakes were made in the treatment they provided.

We have been assured on a regular basis that the trust wants to bring about improvement:

> *…like you I want to ensure that the service is as good as it can be to prevent any further instances like this occurring.* (Aidan Thomas, 4th December 2013)

However, we remain unconvinced by this. A commitment to change cannot be sincere without first recognising that failures have occurred, and that the agent for change is responsible for these mistakes. The Trust acknowledges that Averil died while under their care, and that they are willing to make changes in the future to protect patients, but the two are connected. Changes are needed because the treatment provided by CPFT, as examined in detail above, was insufficient to prevent the worsening of Averil's condition.

Motivations: Relevant Information

We could not comprehend why CPFT would so staunchly deny that any mistakes were made in Averil's care when her death from an apparent series of errors in risk assessment and communication at a number of levels and between organisations indicated that this had been the case. However, recent information has come to light that suggests a reason for such strong denials:

- CPFT was commissioned to provide Norfolk's Community Eating Disorder Service in 2010.
- Their predecessor provider was not recommissioned because of the death of a patient in 2008. The failures made in the case of Charlotte Robinson were highly publicised at that time.
- In May, a tender notice was posted by North Norfolk Clinical Commissioning Group, which announced that the £3.5m contract is to be awarded for the coming years this October.

We believe that Dr Shapleske and those at CPFT who have been dealing with our complaints cannot, and will not, acknowledge their failures due to the need to be contracted for the coming years. It is likely that an admission of responsibility for a patient's death would harm their chances in that process.

9.2. Failure to Apologise for Averil's Death

An apology requires an acknowledgement of one's actions and one's responsibility for them, alongside an admission that those actions caused the outcome complained of. While CPFT has given us their condolences for Averil's death, an apology in its true sense has not yet been given.

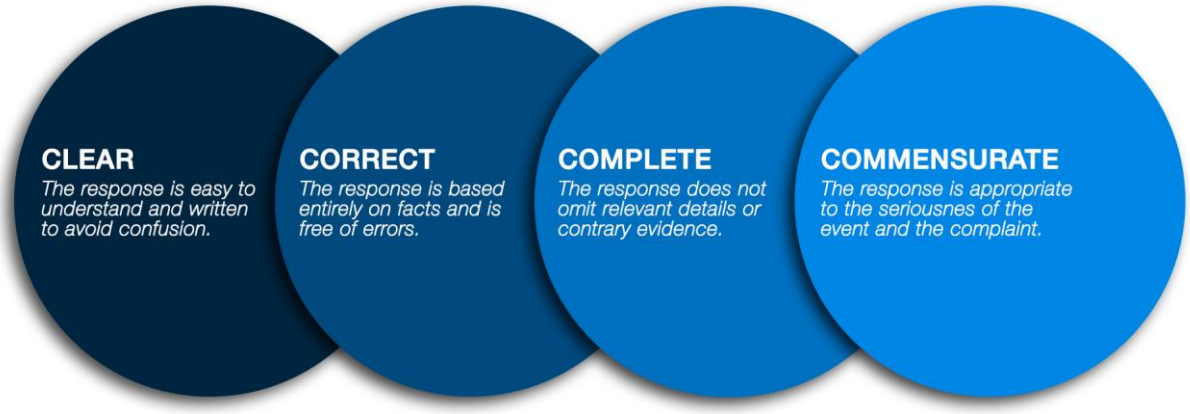
In CPFT's Serious Incident Report, clear acknowledgement is made of several mistakes in treatment:

- The appointment of an inexperienced "trainee" psychologist to Averil's case was not deemed to be clinically appropriate by the reviewing team.
- Averil was not placed on the "high risk" patients list, despite her BMI being discussed in supervisions, as the result of an "oversight" by those clinicians involved, including her psychologist's supervisor.
- The medical review scheduled would not have occurred had it not been for Nic Hart's call to S3 ward, raising serious concerns about her physical state.

In the light of these clear findings of fault within CPFT itself, we have yet to receive an acknowledgement that a more experienced clinician, and better supervisory arrangements, would have prevented Averil's sharp physical decline, and thus, her death.

9.3. Failure to Respond Openly and Honestly to Questions

When a complaint is made by an aggrieved patient or a bereaved family, common sense dictates that the response must be clear, emphasising what decisions were made, why they were made and what the consequences of this were. It must also be correct – free of errors – and must be complete, containing all details relevant to the question posed, even if they reflect badly on the body involved. Finally, they must be commensurate to the complaint made, reflecting the gravity of the event (e.g. patient death) or the allegation made against the organisation (e.g. gross misconduct).



In our experience, responses to our questions have been lacking in at least one of these elements, and an account of all specific failings would be of significant length. This section will outline several examples of the way in which our questions have failed to yield sufficient answers.

Completeness

We have faced several incomplete responses from the organisations involved. The first example of this is our request for the NCEDS team structure, complete with names. In an e-mail dated 18th May 2013 (022/001) we asked:

> *Please provide a clear team structure for the NCEDS service in relation to Averil's care and risk plan with notes on who was responsible for what (ie who made clinical decisions regarding Averil's care? who was able to authorise clinical changes to Averil's care plan ?)*

The original response to this question came in the form of a list of positions:

Role	***Band***	***WTE***
Consultant Psychiatrist		*0.5*
Staff Grade Doctor		*0.6*
Team Manager	*8a*	*0.5*
Team Leader	*7*	*0.8*
Psychology	*8c*	*0.8*
Psychology	*8a*	*1*
Psychology	*7*	*4.3*
Dietetics	*7*	*0.03*
Psychology	*5*	*2*
Admin	*4*	*1*
Admin	*2*	*1*
Total		***12.53***

This did not adequately answer our question – we had asked for a list of names of those in each position. NNCCG did ask CPFT for this information, but a letter from Mark Taylor (041/002) in December 2013 stated that CPFT had committed to these being released in the second week of January. We received them on 12th March (051/001), two months late, and nearly ten months after our initial request.

In our experience, incomplete responses are often disingenuous. We had concerns about CPFT's efforts to learn from prior "near misses" and therefore asked the following question:

> *Had there been any previous Serious Incident's in the local area in the previous 5 years? If so, what were the conclusions in terms of lessons learnt and what measures had been put in place to avoid future harm to patients?*

The response from Aidan Thomas was anything but complete. We had asked whether there had been near misses in the previous five years, regardless of the service involved, as there was a need to learn from such prior experiences:

> *Since the service's inception, there have been no near misses or Serious Incident's…*

In fact, both S3 and NCEDS had discussed near misses and emergencies at one of the family days which the Hart family attended while Averil was at S3. These near misses were within the relevant time period, and were serious enough to provoke the concern of patients' families. The fact that these incidents were under a previous service did not exclude them from our question.

It is also clear from the selections of questions that we have submitted and the responses we have received that certain questions have been avoided. We do not have certainty as to how VP weighed Averil or whether the scales were calibrated, along with numerous other questions.

Clarity

In many questions, the responses given are lacking in clarity, often making confusing statements. For example, we asked Aidan Thomas about the appointment of the Mental Health Care assistant to Averil's care at Addenbrooke's. We had questioned the suitability of the choice, but the answer attempted to explain the role:

> *The bank staff was there to support Averil to minimise the amount of standing and exercise. This in itself is not complex.*

This response is unclear in the context of Averil's care, where she could not actually move her head off the pillow. We are, therefore, no further to being able to analyse the appropriateness of this delegation than we were before.

We also submitted a question asking why high levels of risk were not made known to Averil's family as part of the care plan. The response received included the following statement:

> *Following Averil's death, the service has reflected on the sharing of information when a patient had not given consent for the sharing of information.*

This is close to useless as a statement of change and learning. The service has not offered any proof to show changes, or the way in which the service reflected on the issue, meaning that other patients may still be at risk, and if changes have been made, the family are unaware.

Correctness

Throughout the responses received from CPFT and NNCCG there have been small factual errors and misquoting of evidence. For example, in their answers to our initial questions, CPFT misreport the content of clinical guidelines:

> *In accordance with the Kings College guidelines rapid weight loss was where a person loses 2kg per week. This did not apply to Averil… Should a patient lose more than 1kg a week this should be highlighted as a concern. If a patient loses more than 2kg a week this should be raised as an alert.*

The guidelines are attached at Tab 29, and clearly indicate the points of concern and alert at 0.5kg/week and 1kg/week respectively. This is important for Averil's case, as the gradient of weight loss crosses both concern and alert thresholds at different points in treatment.

However, more significant errors have been made at certain points. We have, for example, been told repeatedly that there was no evidence in Averil's file that she had falsified her weight while under the care of CPFT, but Dr Vize's opinion demonstrates this to have been false.

On 26th November 2013, we asked a set of questions regarding Averil's risk level.

> 1. *Who changed Averil's risk profile from "High Risk" to "Low Risk" contrary to her hospital discharge records?*
> 2. *When and how was this decision made and authorised?*
> 3. *When and how was this decision disseminated to the other health professionals involved and her family?*
> 4. *Did this clinical judgment get passed or communicated to the Primary care team?*
> 5. *Did this clinical judgment get referred to the Addenbrooke's team at S3 who were responsible for looking after Averil for ten months as an inpatient?*
> 6. *Did this change in risk assessment lead to an alteration of Averil's care plan?*
> 7. *Was Averil informed of the change in this risk assessment?*
> 8. *Was this change in risk profile recorded appropriately in Averil's medical records or elsewhere (if so please show us where)?*

> 9. *Given that Averil starved to death in just ten weeks at University without the help she so badly needed, have any of those involved expressed concern that the judgment was completely and fundamentally flawed?*

We felt that we had not received a complete response to them, so sent a further e-mail to ask for answers to them. We received the following response:

> *Further to your enquiry below, our records show that the matter in question was dealt with as follows:*
>
> *Mark Taylor replied formally on 26th November 2013;*
>
> *Following further email correspondence from you, Mark Taylor wrote again formally on 10th December 2013 to say that the questions had been sent to Aidan Thomas' office at CPFT;*
>
> *Aidan Thomas wrote to you formally on 17th January 2014 providing the answers to these and other questions posed.*

The letter from Aidan Thomas is clearly insufficient to answer these questions. In the attached document of responses (at Tab 17), there is no mention of risk save to talk about communication to Averil's family.

Commensurability

The avoidable death of a patient is the most significant type of serious incident that can occur within an NHS Trust. We have submitted detailed questions in order to accurately ascertain what had gone wrong to lead to such an outcome, however, the responses received have not matched the gravity of the event, or the nature of the enquiries.

Several of our questions have received very brief responses, others have, as discussed above, not even answered the question posed. It will be clear from the questions asked and the responses received that the lack of detail has been sufficient to be disrespectful to the family.

9.4. Significant Delays in Responding to Communications

We have submitted several significant sets of questions to CPFT in order to better ascertain what had happened to Averil while under their care. In addition, we submitted our official complaint regarding the transitional care arranged by Sarah Beglin. The date of submission was 8th January 2014, and receipt was acknowledged by Joanne Croxford, PA to Aidan Thomas, the same day.

We received a response to this complaint on 22nd May 2014, after a delay of over five months, which we believe to be unacceptable. Having questioned this delay in an e-mail on 23rd May, Aidan Thomas attempted to justify the delay:

> *As I explained when we last met, the delay was entirely my fault, and I apologise.*
>
> *There has been a significant amount of correspondence over a number of months, and at the meeting we held before last I agreed to consolidate all of the issues… This confused me and I failed to realise there was a separate complaint… I am sorry if this error has caused further distress.*
>
> *Our complaints system aims to get a formal response within four weeks, and I personally sign off all responses. Occasionally where complaints are more complicated this may take longer… I am confident we will be able to comply with these timescales for any future complaint in relation to this case.*

While this accounts for the five months taken to respond, it does not excuse the delay, and does not remedy the significant difficulties this has caused us in proceeding with our attempts to work out what had happened to Averil at NCEDS.

9.5. Failure to Supply Full Medical Records

In the months following Averil's death, we requested her full medical records from CPFT (Letter dated 01/02/2013) in accordance with our rights under the Access to Health Records Act 1990. We were told that a clinician, Dr Shapleske, would review the records to release what could be disclosed to us. The rest, we were told, was protected either by Averil's expectation of confidentiality or by the fact it may cause distress for the family. Only one of these is a recognised exception under the Access to Health Records Act 1990.

The records, a copy of which can be found at Tab 12 in the appendices to this document, were released to us on 20th February 2012. It has since become apparent to us that the records received were not the full record we had expected to receive. Following the publication of Dr Vize's Independent Professional Opinion (discussed below), we became aware of relevant information that did not appear in our copy. The document also acknowledged the length of the records (four volumes), which was significantly greater than those we received.

- Our records contained multiple copies of Averil's discharge summary, along with the notes from Averil's counselling sessions with VP.
- Page numbering began at 344, suggesting a significant volume of evidence from Averil's time in S3 ward which was unavailable to us, preventing us from assessing her history in the form available to those that treated her.
- Almost all references to Dr Shapleske herself had been removed: her name appears on the discharge documentation, which she prepared, and in several e-mails sent during Averil's admission to hospital and treatment at NNUH. Her involvement in Averil's case at S3 was invisible from the records.
- Even within the inter-agency correspondence available, it is uncertain whether or not other e-mails exist, meaning we are unclear as to the level of communications made at the time.

We have since submitted another request for the medical records, which appears to have been dealt with more comprehensively, however, we await the outcome of this process. **Seventeen months later, we are still waiting for medical records to which we have a statutory right.**

We believe that Dr Shapleske fell below accepted professional standards in so heavily editing the medical records, inconsistently with statutory exceptions to their release. This meant that our ability to adequately form a complaint to the Trust was compromised.

9.6. Failure to Adhere to Promise of Separate Physician and Psychiatric Reviews

In a meeting with Mark Taylor, on 9th December 2013, it was promised that a psychiatric review would be commissioned, and following this, a physician's review into Averil's care. It was understood by the family at the time that this physician's review would refer to the care Averil received at NCEDS, as her physical monitoring was an essential part of the care plan.

We have subsequently been informed that our beliefs on this front were incorrect:

- The physician's review is to relate solely to the care Averil received at Norwich and Norfolk Hospital and Addenbrooke's.
- North Norfolk Clinical Commissioning Group does not commission NNUH, nor does it have any responsibility for the care that took place there.
- No independent review will be carried out into the treatment Averil received in respect of her physical condition during her treatment.

We do not understand this decision. It is essential to know whether the physical monitoring received by Averil at NCEDS was adequate, but reviews had already been commissioned into care at NNUH, and a report had been prepared for that at Addenbrooke's. It seems redundant to commission another such review when a significant element in care has not yet been properly reviewed.

9.7. Failure to Assure Sufficient Independence in their Reviewer

Following the promise that a psychiatric review would be carried out, North Norfolk CCG approached the Royal College of Psychiatrists on behalf of themselves and CPFT. We have been assured that this was to be paid for by the CCG or the Trust. Our concerns relate to the way in which Dr Vize, their chosen candidate, was appointed, and the independence of Dr Vize herself.

Appointment Process

North Norfolk CCG approached the Royal College of Psychiatrists in order to commission an independent review into the treatment provided to Averil there. We are told that Dr Vize subsequently volunteered to undertake the process, and that this process is entirely normal. We have also been sent the relevant communications by NNCCG:

> **NNCCG:** *The CCG has been engaged for some months in the resolution of a Serious Incident that occurred last December following the death of a young woman from Anorexia Nervosa.*
>
> *We have reached the stage where we are keen to secure the services of an independent Consultant Psychiatrist with the relevant specialist interest to advise the CCG on the management of her care. Given the specialist nature of Eating Disorder services, and following discussion with Elizabeth, we are hopeful that the Royal College might recommend a suitable professional with whom we might engage.*
>
> **RCPsych:** *I have forwarded it on to the Eating Disorders Section Chair, but he has replied to say that they would need more information to ensure that nobody approached has a conflict of interest. If you could forward any relevant information on to me, I can then pass it back to the Eating Disorders Section Chair to see what he says.*
>
> **NNCCG:** I'm sorry for the delay in reply but am now in a position to advise that the following staff are employed by the local Eating Disorder Service, which names, I assume, you will seek to avoid but do say if I have misunderstood your concerns:
>
> Dr Jane Shapleske, Dr Jaco Serfontein, Dr Louise Brabbins, Dr Madeleine Tatham, Dr Juliette Puig, Veronica Hamilton and Vicki Powell were, at the time of the incident, trainee Clinical Psychologist and trainee Counselling Psychologist respectively.

However, we raised several concerns relating to her appointment, all of which have been ignored or rebuffed by CPFT without taking account of them. This process has been deeply dissatisfying, and is contrary to NHS principles of openness.

Refusal of a Meeting with Dr Vize

At a meeting with Mark Taylor on 10th March 2014, it was agreed that we should have the opportunity to meet with the psychiatrist to discuss our concerns. Our notes from this meeting state:

> *MT [Mark Taylor] stated that NNCCG had enlisted the help of a Psychiatrist from the Wiltshire area to look at the paperwork, case notes and answers provided by NCEDS and the other service providers involved. NNCCG were also looking for an external physician to look at the same records.*

> *NH [Nic Hart] pointed out that the answers so far provided by NCEDS and the UEA medical centre were superficial NHS policy statements in many cases and provided little clue as to the real course of events in Averil's tragedy. NH felt that in the majority of cases the answers had been phrased to mislead the reader and divert from the fundamental causes of Averil's death.*
>
> *NH strongly felt that the process was therefore fundamentally flawed. Any inquiry should be external and be able to look at exactly what went wrong, raise new questions about the course of events, interview those concerned in Averil's care and provide a detailed timeline of what went wrong, when it went wrong and what should be done to ensure no repetition of this tragedy.*
>
> ***NH suggested that the Hart family should have an opportunity to meet and discuss the facts of Averil's case with anyone taking part in an investigation into Averil's death prior to their work. This was agreed by MT.***

Following the appointment of Dr Vize, we once again requested a meeting with her in order to discuss our concerns and check the remit of the review. We received the following response (053/002):

> *Concerning dates for a proposed meeting with the psychiatrist and your subsequent request that this be arranged for next week, I have spoken to Dr Vize this morning who has declined your request.*
>
> *Our request to Dr Vize is to review your daughter's records, which will inform her professional opinion about the judgements of those who cared for her. Your request for a meeting is out-with the boundaries of this work, which is conducted wholly off-line.*

We were, naturally, unhappy with this response. However, we were subsequently advised by Diane Collier that we would be able to meet with Dr Vize, but no explanation for this change of heart was given at the time:

> *I am writing further to recent correspondence concerning your request to meet Dr Christine Vize, the consultant psychiatrist whom the CCG has asked to provide an independent opinion about Averil's care.*
>
> *In discussion with Dr Vize this afternoon, she has consented to meet you at her office in Marlborough, Wiltshire and has offered the following dates: [5th, 10th, 12th June 2014]*
>
> *Please would you be kind enough to advise if one of these dates is suitable and whether you will be accompanied by any other party. For clarity, Dr Vize has earmarked a period of 2 hours in her diary on each of these dates; I will provide the full address in due course.*

We decided not to proceed with this, because we already had significant concerns about the remit of Dr Vize's review, and her independence within the process. These will be outlined below.

Declaration of Interest

We were dissatisfied with the selection of Dr Vize due to evidence that she worked closely with Dr Shapleske in various organisations. As a result of this, we asked Mark Taylor the following:

> **1.** Has Dr Vize "worked with or been involved with - in a professional capacity or socially", in any way, any members of the NCEDS team (past or present) over the past ten years. If so, please can you advise in what capacity Dr Vize has been associated with each these individuals?

This did not receive a response. Diane Collier did, however, confirm that:

> *Concerning your request for her CV for your consideration and information, I am advised that details of her background and experience of this kind of work will form an integral part of the report that she will produce for the CCG, a copy of which will, of course, be provided to you.*

In her Declaration of Interest, Dr Vize discloses several connections to those involved in Averil's care:

- Psychiatric training at Cambridge from 1987-1991, which overlapped with Dr Shapleske's training, and included research work in the field of eating disorders.
- Professional contact with both Dr Shapleske and Dr Serfontein, sitting on the EDSECT committee and the Clinical Reference Group at the Royal College of Psychiatrists.

We have subsequently asked both Dr Vize and the Trust to confirm whether or not she and Dr Shapleske had personal contact in addition to this professional contact outlined. However, we remain convinced that **other, more independent reviewers could have been chosen.**

9.8. Failure to Include the Family's Concerns in the Remit of the Review

In our questions to Mark Taylor (mentioned above) we also asked:

> **2.** Has Dr Vize been informed that the "inquiry" as it currently stands, is against the RCPsych MARSIPAN guidelines in cases where there has been a serious incident or death?
>
> **3.** Has Dr Vize been informed that Averil's family are totally against the ad hoc approach to the current "investigation" and that they are looking for a properly convened external inquiry with an agreed remit and terms of reference. Such an inquiry would involve the family from the outset.

We received no answer to these questions, and despite our protestations, the independent professional opinion has continued without the family's concerns being included in the remit of the review.

Although she begins by explaining that "NNCCG have specifically asked for the report to cover points relating to matters raised by A's father," Dr Vize reports that she had the following information from us:

- Questions raised by Nic Hart in September 2013 and December 2013 concerning the care of his daughter by NCEDS and UEA Medical Service and the responses.
- Questions raised by Nic Hart concerning Averil's care by NNUH pertaining to their relationship with NCEDS and responses.

These questions were, by the time of the review, six months out of date – we had received more information since they were written, and wished to amend them and explain our concerns to the reviewer in order that they were taken into account. The remit presented to Dr Vize included:

> *Please examine the evidence to determine the quality and timeliness of the transition of care between Addenbrooke's Hospital (Cambridge University Hospitals NHS Foundation Trust) and the Norfolk Community Eating Disorders Service (NCEDS).*
>
> *Please examine the nature, content and timing of the care plan to be delivered by NCEDS and the UEA Medical Centre, including risk management and contingency planning. To what degree would it be expected that a representative of an Eating Disorder Service would visit the primary care team to discuss the care plan? What would be the expected timeline for the first appointment with a patient in these circumstances?*

> *Please examine the monitoring of the progress of the care plan, and the effectiveness of communication between NCEDS and the UEA Medical Centre. To what degree would the consultant lead for an Eating Disorder Service meet with / review the care of each patient?*
>
> *Please provide an opinion as to whether the degree of consultant psychiatrist involvement, and the degree of involvement of NCEDS with Addenbrookes' Hospital following admission was appropriate to the circumstances.*
>
> *Please provide an opinion on the quality, extent and timing of the notes entered into the patient's health record, belonging to Addenbrooke's Hospital and NCEDS.*

This failed to take into account our greatest concerns, which relate to basic elements of Averil's care. ***What was the experience of VP, and was her appointment to Averil's case appropriate? Were her decisions acceptable, and was supervision provided to an appropriate extent?***

These issues are not directly addressed, and Dr Vize engages in fence-sitting when they are discussed, refusing to reach a particular conclusion on them:

> *A was seen regularly in the community by a qualified but inexperienced practitioner who was supervised by an experienced senior clinician… it is not possible to speculate on whether a more experienced therapist would have noticed anything different, or not.*
>
> *Without having incontrovertible evidence that the weights were wrong, it would not be reasonable to speculate whether any clues were missed, and it would not be reasonable to further speculate on any link to the experience of the therapist.*

This, in itself, does not adequately resolve the issue of VP's suitability to Averil's case, regardless of her risk level, and the fact that she was not re-assessed for risk in light of her weight loss after she was discharged. Dr Vize proposes two alternative scenarios at paragraph 107(e)(i-ii), but both implicate VP's lack of experience if either could be demonstrated. Even in the absence of certainty as to which scenario actually occurred, experience remains highly relevant to the evaluation of the care provided by NCEDS, and the way in which it could be improved.

9.9. Individual Concerns with the Vize Review

While our greatest worries regarding the independent professional opinion prepared by Dr Vize relate to the remit and to the failure of NNCCG to assure sufficient independence in their choice of reviewer, we have significant concerns with the content of the document that has been shared with us.

Failure to Critically Assess Treatment Provided at NCEDS and UEA Medical Centre

We have already discussed VP's lack of experience in Anorexia Nervosa. Dr Vize discusses the treatment provided by Vikki Powell, but does not consider her suitability to coordinate care:

- No questions are raised of VP's suitability to weigh patients. We have no reason to believe that she had specific training for the weighing of patients with Anorexia Nervosa.
- Dr Vize took no account of the protocols at NCEDS mentioned in the SI Report, which stated that it was the practice of the Unit to consider all patients of BMI <15 to be high risk. The failure to do so due to oversight is not criticised at all.
- VP is stated to have recorded weights, rather than BMIs, yet no criticism is made of this in the final opinion, yet an incorrectly calculated moving average created a false impression of an increase in weight trajectory, rather than a continual fall.
- Dr Vize describes VP as "qualified but inexperienced" but makes no distinction between being qualified, and being competent to practice with patients, or to undertake these measurements.
- Dr Vize concluded that UEA Medical Centre "did what was asked of them." However, there is very little evidence to suggest that this was the case. Even on a restrictive interpretation of

VP's second letter, Averil would have required physical monitoring including blood pressure on a regular basis. This was not provided even once.

- Dr Vize made no reference to the care co-ordinator role, or the requirements of the position. The appointment of an inexperienced 'trainee' within the context of the duties of care co-ordination is not raised at any point.

By contrast, Dr Vize found points at which to criticise the Norwich and Norfolk Hospital extensively:

- Dr Vize heavily criticises NNUH for failing to share information with the NCEDS team, stating that there did not seem to be a rationale for such restrictions.
- She also takes exception to the fact that Eating Disorder behaviours went unnoticed over the weekend after Averil's admission. We have explained, however, that such behaviours also went unnoticed and unaccounted for by staff at NCEDS.

Inconsistent Conclusions

Dr Vize reaches several conclusions in her opinion. While some of them remain logical, there are certain points at which they become contradictory:

- At 107(b) she also concludes that Averil could not have been falsifying her weight because she only did once as an inpatient, and then admitted to it. However, outpatients are known to have higher rates of weight falsification (Jaffa, 2011), and without prompting, it is unlikely to have been admitted to.
- At 107(c) she suggests that the weights recorded by VP would have been consistent with the food diary that Averil reported. However, VP had noted in Averil's file that the food intake was not sufficient to effectively increase weight, even though her recorded weight rose.
- At 107(d) she notes that Averil's father compared her appearance to that when she was admitted to S3 as an inpatient, yet she does not give any weight to this evidence, despite the fact it is indicative of the path her weight loss followed.

It is the path of weight loss that is problematic. Dr Vize proposes two alternative weight trajectories with tentative explanations (107(e)(i-ii)), including either regular weight loss with weight falsification, or sudden unprecedented weight loss:

> *(i) Despite the lack of history of such behaviour and evidence for it, the weights prior to 07/12/2012 were not accurate, and A's weight was declining faster and further than the figures suggest. This alternative implies that she had been falsifying her weight, and either she was trying to disguise her appearance or the change in it had not been noticed. When her father and sister became concerned and the medical review was scheduled, she panicked, cancelled the appointment in order to try and avoid being discovered, and used her grandmother's death as an excuse. She had also reduced contact with her mother to reduce the extent to which she had to deceive her.*
>
> *(ii) A's weight declined massively and dramatically in a 2 weeks period. When she was initially admitted to S3 in 2011 her overall weight loss was 19kg over 7 months, but because she was only newly referred, it is not possible to determine whether there was a similar drastic decline then. I would have concurred with the clinical opinions in previous reports that losing 8kg in 2 weeks was virtually impossible, but have recently seen a patient who genuinely seemed to have lost 5.8kg in the week between (routine) referral and assessment, and whose blood tests had gone from normal to showing multiple abnormalities within that time. This patient had drastically reduced both food and fluid intake and had been exercising. A's clinical state on admission to NNUH indicates she could have been doing likewise.*

It would not be possible, she concludes that without incontrovertible evidence that the weights were wrong, it "would not be reasonable to speculate whether any clues were missed", and it would "not be

reasonable to further speculate on any link to the experience of the therapist." As explained above, this approach fails to adequately examine the treatment provided, but it also seems inconsistent with other conclusions reached elsewhere:

- At 145, Dr Vize concludes that a crisis plan with a BMI at which readmission would have occurred would have been useful, but that it was *"unlikely to have altered the outcome, because of the discrepancy between the observed and actual weight."* This presupposes the "falsification of weight" hypothesis is correct.

Capacity and Consent

Averil is reported as being "over-optimistic" throughout her treatment at S3, NCEDS and even at NNUH. She had little grasp of the condition from which she was suffering. Dr Vize touches on this, but does not adequately question it: if it was known about, and mentioned in the discharge summary, why was it not taken into account by those treating her at NCEDS or at UEA Medical Centre?

9.10. Failure to Accurately Record Meetings

We have been informed on a regular basis of the importance of obtaining information in writing, rather than face-to-face at meetings, which cannot be relied upon. We originally set out to acquire answers to our questions in writing, after which we could meet and discuss a clear account of Averil's death with those involved, to find out what changes have been made. However, many of the questions and complaints submitted to both CPFT and NNCCG have elicited the following variety of response:

> *We can provide a more detailed answer at the proposed meeting.*
>
> *This is best explained at the forthcoming meeting.*
>
> *I would stress that these are initial answers. There is in fact more detail to the answers to some questions, which we believe will be much better presented to you face to face and we will therefore do that when we meet.*

We originally accepted such a solution, as we believed we could trust that minutes of meetings would be prepared that truly reflected the discussions held. However, we have been disappointed at the difference between the minutes recorded and the content of the meetings themselves.

At a meeting on 9th October 2013, we discussed various topics with Mark Taylor, but the 'minutes' of the meeting, which act as a record of what was discussed, are incomplete. Our notes from this meeting record the topic of conversation, the statements made, the response to those statements and the outcome reached. The NHS responses represented general topics accompanied by stock responses, which do not always match those given in the meeting:

> *At the meeting we discussed the following, variously: […]*
>
> - *The primary care team's failure to undertake the investigations recommended by Dr Sarah Beglin following her risk assessment of Averil's case; […]*
> - *The failure by NCEDS to respond appropriately to your telephone call following xxxxxx's admission to Addenbrookes Hospital, saying that they 'had it all in hand' - but taking none of the action you felt entitled to expect;*

We were dissatisfied with such summaries because they failed to take into account the CCG's response to our particular concerns, and the actions that they claimed would be taken. Similar concerns can be raised of other meetings, and will be clear from e-mails detailed in the appendices.

9.11. Failure to demonstrate that changes have been made

Although NNUH have acknowledged failures and a desire to put them right, we have seen little evidence of this from NNCCG and CPFT. Some mention has been made of tentative changes, including the way in which risk is managed, but specific promises to integrate the Hart family into the change-making process have been broken.

In a letter dated 25th October 2013, we were told:

> *Meetings with local Acute Trusts to introduce and embed MARSIPAN principles are occurring and once this programme has been completed, the MARSIPAN Group will be established. The contribution of your experience to this Group will clearly be invaluable and Jackie will ensure that your input is invited.*

We are yet to hear about arrangements for this process, despite several prompts to find out.

10. UEA Medical Centre

Throughout the complaints procedure, we have been unable to obtain comprehensive responses to our questions to UEA Medical Centre. They have failed to provide any sense of openness and honesty in their dealings with us, and have not provided any justification for doing so. North Norfolk CCG have since informed us that the reticence to answer our questions is based on advice from the Medical Defence Union to remain "cautious in replying" and not to share "potentially litigious information."

Failure to Respond to Communications and Questions

NHS guidelines are clear in specifying that in serious cases where a patient has died, the NHS Trust concerned must communicate with the family in an open and honest matter. In our initial complaint to NHS England, we established the extent to which UEA Medical Centre had responded to our questions inconsistently with these values. We sent several letters asking questions about Averil's treatment in order to work out what had happened. However, answers to these were not forthcoming. The centre was evasive, and ignored the issues we raised.

On 2nd April 2013, we asked what health checks were carried out, and for a copy of Averil's medical records. We received a response on 5th April, which simply stated that the University holidays meant that staff were away, and that it would be beneficial to wait for their return. Following this, we were given Averil's medical records (11th April).

The first full response we received arrived on 23rd May, and followed our request for North Norfolk CCG to intervene in the process. This response gave a brief outline of the treatment Averil received, and then simply stated:

> *We have carried out an internal enquiry into these sad events and steps have been taken to ensure that all colleagues are aware of the guidelines issued by King's College and of training and refresher courses.*

We wished to raise further issues, as the findings of the review were not shared with us. We subsequently sent letters asking specific questions on the 12th June, 21st June, 26th June, 4th July and 15th July, to which the sole response was a letter on 1st July, confirming that Averil's medical records had been sent to NNCCG.

It was North Norfolk CCG that assisted us in obtaining the information we needed, helping us assess the medical records and the information they contained, and obtaining a letter (at Tab 4) on 31st January 2014, which responded to our questions.

This letter contained some inaccuracies. For example, at the second bullet point, Dr Sargen says that the discharge summary required the medical centre to check Averil's "physical weight" every week and to monitor bloods every 2-3 months. This document in fact states:

> *GP: Please check Averil's physical health every week (weight, BP, heart rate and level of physical strength – squat test). Please monitor her bloods every 2 to 3 months…*

By contrast, the full care plan asks:

> *To be weighed weekly and to have bloods every two months during the early stage of discharge and at University.*

The document referred to, given the regularity of blood tests and use of the word "physical", is the more specific one, imposing clear monitoring requirements. Against these standards, which were followed by Dr. Clarke on the 25th October 2012, the care provided after that date is inadequate.

11. NHS England

We submitted our complaint about the Primary Care provided by UEA Medical Centre on the 29th November 2013. This was acknowledged by Dianne Gypps, who was to lead the response to our complaint, with the reference number 1382/175860. The document can be found at Tab 19, but contained several key issues raised with care:

> *6.1. Failure to follow the basic risk assessment for Averil Hart, leading to the neglect of a high risk patient and preventable death of a young person suffering from a treatable illness.*
>
> *6.2. Failure to provide adequate patient safety and adhere to the Care Plan provided by Addenbrooke's leading to the death of a high risk patient, who the UEAMC had already designated as being in a "dangerous" transitional period in her life.*
>
> *6.3. Failure to undertake the simple weekly patient health checks as prescribed in Averil Hart's discharge plan from Addenbrooke's hospital, leading to the death of a high-risk patient. […]*
>
> *6.6. Failure to communicate with outside related agencies (NICE guidelines) which lead others to believe that care was being provided (as prescribed) when effectively no or less than minimal care was being given.*
>
> *6.7. Failure to communicate changes in care plan activity to outside agencies.*
>
> *6.8. Failure to provide emergency care (caused by lack of communication and proper liaison / working methods) with the University disability service and University student's dean's office, as would be reasonable to expect from a university medical service.*
>
> *6.9. Failure to assess incoming communication from a patient within the context of their illness and take appropriate action.*
>
> *UEAMC have cited as an excuse for the lack of care they provided for Averil, an email that they received from her. Given that Anorexia Nervosa is a psychiatric disorder with one of the highest mortality rates of any mental health illness, it is inconceivable that an email from a mental health patient should be cause for any cessation or reduction of care without proper health checks and a referral to specialist health professionals…*

We supplemented this with specific complaints about the way in which our communication following Averil's death had been handled:

> *6.12. Failure to provide open and honest responses and communication with Averil Hart's family, following Averil's death. Failure to respond in full to ten letters from the Hart family [a table of dates is attached in the full version of our complaint].*
>
> *Failure to provide a copy of the internal inquiry at UEAMC when requested.*

Our concern has been that the full substance of the complaint was not recognised. The nature of the complaint is the way in which the medical centre failed to follow guidelines, failed to follow instructions, failed to consider the nature of Averil's condition, and then failed to hold themselves accountable in any way for their lack of provision. This was not reflected in the initial response our complaint received from NHS England.

11.1. Failure to Identify the Substance of Our Complaint

The response, dated 16th December 2013, included a summary of the complaint, with the key issues that were to be investigated. While the summary identified four issues, three were contextual, and only one related to the quality of treatment. They were as follows:

> *Averil attended the University of East Anglia in September 2012, and died within 10 weeks.*
>
> *She had been discharged from Addenbrooke's Hospital in September 2011 suffering from Anorexia Nervosa.*
>
> *The University were notified by Addenbrooke's that Averil was a "high risk of relapse" and that weekly check-ups needed to be established to monitor her.*
>
> *The complaint is that no monitoring was established by the University Medical Centre and that Averil's care was neglected.*

We had significant concerns that the substance of our complaint had not been acknowledged. We raised specific concerns about the appointment of individuals to Averil's care, the way in which the case was to be handled following this basic failure. While the letter did note that "this is only a summary and your original complaint will be used for the investigation", we were worried that the summary was evidence of inappropriate complaints management.

11.2. Inaction on Transfer of Complaint to NHS England

Due to our worries, we requested that our case be transferred to NHS England, rather than its NHS East Anglia Complaints subsidiary. This e-mail request and acknowledgement (045/001-002) was followed by correspondence with Dianne Gypps to explain that we had requested the case be transferred from her, and that it would be managed by NHS England.

Despite subsequent telephone confirmation from Mrs. Gypps that the complaint has been transferred back to a case manager at NHS England itself, we are yet to receive any update on the complaint and its progress. We hope that the ombudsman may be able to ascertain what communications have been made with the organisations involved, and the progress of our complaint.

12. Norwich & Norfolk University Hospitals NHS Foundation Trust

Averil's treatment at the Norwich and Norfolk Hospital fell below the standard we expected, and showed a lack of awareness of Anorexia Nervosa and appropriate treatment methods. We submitted a complaint on January 9th 2014 detailing our concerns:

> *1.0. Failure of N&N to ensure an appropriate assessment of Averil's mental capacity as per MARSIPAN guidelines, with no use of the [Mental Health Acts] to ensure Averil's safety. […]*
>
> *1.2. Failure to ensure commencement of appropriate treatment for a patient in a critical condition in a timely way. Averil's family were told that Averil would be sent home after the weekend. Clearly this was an inaccurate and inappropriate assessment of her condition. […]*
>
> *1.4. Failure to assign appropriate staff to a patient in a critical condition. (With knowledge of Averil's condition and capable of dealing with a condition where after several days with no nutrition, glucose levels would be critical).*
>
> *1.5. Failure to ensure Averil's safety with regard to mobility on the ward.*
>
> *1.6. Failure to prevent patient mobility in extreme AN, allowing Averil to use critical reserves of energy, which resulted in her condition deteriorating substantially.*
>
> *1.7. Failure to provide nutrition in an appropriate way (expecting Averil to feed herself from the ward trolley – a virtual impossibility in critical stage AN).*
>
> *1.8. Failure to prevent Averil from falling and sustaining a head injury. […]*
>
> *2.0. Failure to involve other specialist agencies in a timely manner, […]*

Our complaint was acknowledged by NNUHFT on 16th January 2013, and we received a written response within the appropriate time guidelines.

12.1. Inadequate Initial Response to Concerns

We received the response to our complaint on 14th February 2014. This response gave an account of Averil's treatment that was deficient in several ways, not accepting responsibility for any errors made. Several points are worth noting. First, the account of Dr Serfontein's advice is inaccurate, and was not as a result of the team's recognition of the importance of immediate liaison:

> *The team also fully recognised the importance of immediate liaison with a mental health team familiar with the treatment of eating disorders. As a result of this, Averil's admission was discussed at 16:20 hours on 7th December 2012 with Dr Jaco Serfontein, Lead Consultant Psychiatrist for the Norfolk Community Eating Disorders Service (NCED). He gave the team guidance regarding Averil's care on the ward and arranged to see her on 10 December 2012 (the Monday after the weekend).*

Averil's medical file contains Dr Serfontein's account of this conversation, which demonstrates the inconsistency in their report:

> *I phoned the N&N. They cannot give me information about her on the phone, but said that she is currently still in MAU and will be admitted under Gastro. They would expect that she will still be on the ward on Monday.*

This suggests that any advice was given at Dr Serfontein's insistence, and was based on limited information. There appears to be no record of this discussion in Averil's notes, or in the medical review prepared by Dr Alastair Forbes on the 5th March 2014. The only account of such a discussion is in relation to a phone call on 11th December, documented by Sarah Beglin.

Additionally, the conclusions reached were inconsistent with those reached by Tony Jaffa, in the Serious Incident Report prepared by CPFT. Dr Jamieson believed that:

> *The suspicion was that Averil had suffered a significant acute liver injury as the result of an accidental overdose of Paracetamol and probably in addition, Ibuprofen… Dr Jamieson is of the opinion that this was a significant factor in her deterioration and contributed to the need to transfer her urgently to Addenbrooke's…*

By contrast, Dr Jaffa notes:

> *It remains unclear if AH did consume too much paracetamol… as she reported knowing about the need to modify such use and dosage.* ***Her blood and liver function results at the N&N were consistent with severe malnutrition due to Anorexia Nervosa and, as far as the investigation team are aware, did not show high Paracetamol levels.*** *This is reported from NCEDS medical clinicians rather than the information received by the N&N*

No test appears to have been carried out to confirm the level of paracetamol ingested, and very little account seems to have been taken of the significant role of Anorexia in leading to liver failure, even if some level of paracetamol toxicity was involved.

Following these significant flaws in the response to our complaint, the summary included at the end of NNUH's response was a simple denial of any failure:

> *In summary, Dr Jamieson believes that MARSIPAN guidance was met and every effort was made to liaise promptly with the psychiatric team as the risks and challenges of treating a very sick young woman with Anorexia Nervosa were recognised by staff. The severity of her liver failure was, in Dr Jamieson's view, a significant contribution to her deterioration. The deterioration in her liver function together with her ongoing worsening condition, prompted an appropriate transfer to Addenbrooke's Hospital.*

We do not believe that this answered our concerns. The inaccuracies in the letter, and the failure to respond to our specific points made relating to minimising movement and the choice of an inappropriate feeding mechanism had not been adequately dealt with. The letter simply stated that decisions had been taken, without explaining why they were appropriate with reference to guidelines.

Reconsideration and Later Course of Action

In the months following this response, Norwich and Norfolk University Hospitals NHS Foundation Trust altered their response to our complaint, acknowledging the need for changes to be made. In March, the Hospital commissioned a Medical Review and Report, which were based on the contemporaneous records. Dr Alastair Forbes, one of the members of the MARSIPAN committee, was appointed.

On 13th April 2014, we met with Dr Forbes and Anna Dugdale, of NNUH, who were able to explain the findings of his medical report and discuss appropriate next steps. They agreed that an independent review should be carried out into the treatment provided, to ensure that improvements could be identified and made for the protection of others in the future. This was confirmed in an e-mail from Anna Dugdale following the meeting:

> *I thought I would just drop you a quick line to confirm as agreed that I will make contact with Paul Robinson and invite him to review both Averil's care and also the guidelines we*

have in place for the care of patients admitted with acute anorexia. I will ask him to review with the aim of identifying things we could improve. I will of course share with you the action plan resulting from the review and would be delighted if you and your family were happy to come in to discuss this with us. I will talk to the Vice Chancellor at UEA before approaching Paul in order that we have a clear and joined up approach to our review.

I hope that Alastair's review and input was helpful as a start point and that you are feeling assured that we are determined to learn and improve from Averil.

We are happy with this approach, despite the delay in reaching it, and eagerly await its outcome. It was the first acknowledgement of any accountability for Averil's death we received, and the first offer of a truly independent review, motivated by improving the quality of care.

12.2. Subsequent Administrational Errors

The subsequent meeting with Paul Robinson took place on 7th July 2014, and involved discussion of the case and key points relating to it. However, we were disappointed to find that our complaint had not been passed to him, and a copy had not been prepared for the meeting. He had been given only our submission to another inquiry, written a year earlier. It was a disappointment to find such poor administration after receiving a positive, engaging response.

13. Cambridge University Hospitals NHS Foundation Trust

Averil's treatment at Addenbrooke's fell below the standard we felt entitled to expect, and was a significant contributing factor in her death. We submitted a complaint on January 9th 2014, which detailed Addenbrooke's Hospital's failures:

> *1.0 Failure of Addenbrooke's to ensure an appropriate assessment of Averil's mental capacity as per MARSIPAN guidelines, with no use of the [Mental Health Acts] to ensure Averil's safety.*
>
> *1.1 Failure to instigate safety procedures to ensure that Averil's blood sugar levels were maintained at a safe level, resulting in a major seizure with catastrophic results.*
>
> *1.2 Failure to ensure commencement of treatment for a patient in a critical condition in a timely way. […]*
>
> *1.4 Failure to assign appropriate staff to a patient in a critical condition (with knowledge of Averil's condition and capable of dealing with a condition where after several days with no nutrition, glucose levels would be critical)…*

We hoped that the hospital would outline events in respect of our individual concerns, and explain the ways in which failures had been acknowledged and changes made as a result. They did not do so.

13.1. Failure to Respond to Complaint

The response received from Addenbrooke's was inadequate, simply referencing the report that had been prepared in the weeks following Averil's death. We were told:

> *You will note the key findings of the report and the identification of where care and treatment could be improved… In terms of your specific questions, we believe that these have been addressed in the Serious Incident Report. In terms of your specific requests, we do not believe that an external investigation is required given the breadth and scope of our own internal investigation.*

This response was insufficient. Our complaints related to grave failings made at the time of Averil's death, which require a commensurate response, providing more detail for peace of mind. The SI Report itself makes wide recommendations, which are not detailed enough to assure us that the faults that contributed to Averil's death have been remedied.

Safety procedures for maintaining blood sugar levels and carrying out routine tests are not discussed, and are of more general importance than just Anorexia Nervosa patients. The Mental Health Act 1983 is not mentioned, except to acknowledge (at p.2) that detention was not considered necessary at the time. It was this decision that motivated our concern about their use, as proper protocols are required to ensure that they are deployed in a timely manner for future Anorexic patients.

> **Further Questions:**
>
> - What further changes have been made to ensure that patients are detained in a timely manner when their agreement to treatment may be temporary?

Further Evidence (Tab 31)

The importance of our submission is underlined by recent communications with others who have been inpatients at S3 Ward, outpatients at NCEDS, or outpatients treated by the same clinicians. While our concerns that “near misses” under NCEDS’ predecessor unit were dismissed on the basis that the new unit was structured differently, the accounts we have received from others treated by the same clinicians show that the standard of care has not improved. There remains a perception within both organisations that Anorexia Nervosa is an illness of choice, yet this could not be further from the truth.

We received this e-mail on 16th August 2014, from Patient A, who had been treated at S3 Ward at the same time as Averil, and also studied at UEA, where she received care from NCEDS:

> *I'm an ex patient from s3 and was with your daughter on her first day and her last day at s3 and I'm so so sorry for your lose she was a truly wonderful girl. I've been recovered now for over a year but have been under both s3 and Norfolk and Norwich community ED services and I couldn't agree more with everything you are promoting as have been through all of this. I first came to s3 with being slightly underweight with a BMI of 16 before staying there 10 months and becoming iller on my time at s3. I was then discharged with a BMI of 13. When I was told they could not help me unless I wanted to get better. They offered me and my family no support with this leaving my family completely distort [distraught] and me at a very high risk.*
>
> *After 5 months at being at home and having two near heart attacks and dropping to a BMI of 9 did me and my family plead for them to take me back. I stayed another 8 months were I [fought] hard with very little support from staff as there was a huge lack of staff. And my family brought in [their] own counsellor from another services was I discharged but they discharged me when I was doing well but not at a healthy weight still me and my family were completely cut from the services when I was discharged and I was offered no support.*
>
> *Once I moved to Norwich to start Uni I joined the Norfolk team but was on a waiting list for 3 months then once I start therapy I was only offered 45 mins every 4 weeks. I'm lucky that I have been able to have the strength to recover with support of family and friends but I too agree that there are massive loop wholes with in the NHS system. And with on the wards of s3. They are very relaxed on that ward and the recovery rate is very low with a majority of patients staying there for up to 2 years without making any form of recovery […] There needs to be massive changes with both services and I don't think the wardens or the NHS are generally aware of what's actually happening.*

Patient B, a PhD student in Cambridge who was treated by the Adult Eating Disorder Service at S3 and as an outpatient, wrote to us on 11th August. Her care involved some of the clinicians that treated Averil:

> *I have had anorexia since 1989. All of my adult inpatient stays, from 1998 onwards, have been at the EDU run by Birmingham and Solihull Mental Health Foundation Trust. From the 1990s to 2008, this was called the REED unit, although it is now in a new building and renamed Cilantro…*
>
> *From 2001-2002, I had several outpatient appointments at Addenbrookes with Professor Dowson, a personality disorder specialist who ran a "low weight clinic". This was not very helpful and after 4 terms, it was clear that I needed to transfer my care back to Birmingham. Thankfully, the Cambridge GP agreed to see me as a long term "temporary resident", allowing me to re-register with my home GP, which then meant I was once again under Dr Robertson at the Reed unit. By the end of my second year of uni, I was very poorly and*

was admitted to the Reed following a collapse. I spent just over 12 months as an inpatient before returning to Cambridge to finish my BA…

In August 2007, I wanted to return to my PhD and Dr Robertson was concerned that I needed more ongoing support that I'd been able to receive from his team while living in Cambridge. I therefore agreed to be referred to the eating disorder team at Addenbrookes, after he had reassured me that CPFT had now got a specialist service and I wouldn't have to see Professor Dowson again.

Despite Dr Robertson requesting an urgent referral […] after moving back to Cambridge and restarting my PhD on 14th August 2007, I didn't get an appointment with Cambs EDS until the end of October 2007. (In 2011, they acknowledged in a meeting that this was a failing on their part). By the time I was seen, […] the progress I'd made as an inpatient had been lost and my life was dominated by my anorexia. The result of the assessment was that they would offer me some therapy. They said I needed it urgently.... so put me on an "emergency waiting list."

My first session did not take place until January 2008, 5 months after my discharge from inpatient treatment. The therapy… was not a positive experience for me. The therapist seemed to have a lot of preconceived ideas about me and told me, amongst other things, that I'm "an anorexic with no hope of getting better", "the amount of treatment you've received in Birmingham prejudices what we will offer you", "nothing has been proven to work with you".

I asked to have an appointment with the ED psychiatrist to discuss my medication and was told this was impossible. Similarly, when I asked for a dietetic appointment, I was told that they never offered outpatient appointments with dieticians. A friend from university was, at that exact time, seeing an S3 dietician as an outpatient so I knew this was a lie.

After 11 sessions, in August 2008, I was told that the therapy would finish next session because we had completed our 12 session block. I chose to finish on that session since I couldn't see the point of coming back for one more. Having seen my notes, I now know that the therapist misreported this conversation and wrote that I discharged myself on the 11th session out of a possible 24. Once again, this is simply not true. She said she was discharging me after 12 sessions because I wasn't making progress and they didn't feel they could offer anything else to me given the amount of "unsuccessful" treatment I'd had in the past and I chose not to have the 12th session. (incidentally, I - and the Birmingham team - disagree with the "unsuccessful" adjective since each round of treatment has been successful in getting me better than I was when I was admitted, arguably saving my life many times).

I managed to hand in my PhD at the end of June 2010. CPFT complaints manager had arranged for a general consultant psychiatrist to see me several times but she moved jobs in July. I was given an appointment with a different psychiatrist in Sept 2010. This psychiatrist said that since CPFT EDS had, in her words, "given up on me", unless I wanted to "give up on myself", I should ask my GP if the PCT would fund inpatient or day treatment for me elsewhere. If not, she told me that she felt my only option would be to move house because she did not think that general psychiatry were well placed to be in charge of my care.

I asked my GP whether this would be possible. But in October 2010, she had a telephone conversation with Dr Shapleske (whom I had never met), during which Dr Shapleske told her that the problem with me was that I didn't want to get better and their service wouldn't see me until I'd "made the decision to recover". This seemed completely bizarre to me: why would I be trying so hard to get treatment if I didn't want to recover? And surely an

EDS is used to patients with ambivalence to treatment given that it is a well-known feature of eating disorders?

Based on this conversation, it was clear that there was no point re-referring me to Cambs EDS and the GP practice wouldn't fund treatment elsewhere.

As soon as I was able, given commitments for my post-viva PhD corrections and some supervisions I was doing that term, I left my home in Cambridge and moved back to Birmingham. I had gone up in November to re-register with my old GP and was able to speak to Dr Robertson on the phone in early December. He arranged to see me in clinic on Dec 21st. He wanted to admit me to the ward as soon as possible. I asked to wait til after Christmas rather than going in on the suggested date of 24th Dec. The next available admission date was 30th Dec. I was so poorly on admission that tubefeeding was required and I was sectioned on 31st Dec 2010.

The similarities between these two individuals' experiences, even years apart, are striking. Both were told that they did not want to get better by those running the same unit, while both also felt the impact of resource constraints. It has become painfully clear to us that the service that Averil used had not just failed her, but continues to fail others on a regular basis.

We have also received e-mails from the relatives of those who died as a result of the failings of other services across the country. The problem is not limited to NCEDS and the Cambridge services, but extends further, suggesting a need for wider review by the Ombudsman. In 2004, the Scottish Ombudsman reviewed a similar case, involving a patient with Anorexia Nervosa. The report into that case led to a national review of services for patients with Eating Disorders at a governmental level.

Table of Appendices

Tab	Description	Dates (If Applicable)
1	Table of all E-Mail / Postal Communication with NNCCG / CPFT	01/01/2013 – 11/08/2014
2	Copies of Postal Communication with NNCCG	01/01/2013 – 11/08/2014
3	Copies of Postal Communication with CPFT	01/01/2013 – 11/08/2014
4	Copies of Postal Communication with UEA Medical Centre	01/01/2013 – 11/08/2014
5	Submission by Nic Hart to the Serious Incident Inquiry carried out by CPFT. Submission by Miranda Campbell to the Serious Incident Inquiry carried out by CPFT.	18/03/2013 18/03/2013
6	Serious Incident Inquiry Report prepared by CPFT. Authors: Mike Bell, Kyran Brivio, Tony Jaffa	13/05/2013
7	Serious Incident Inquiry Report prepared by Cambridge University Hospitals NHS Foundation Trust (Addenbrookes). Author: Dr SB, Consultant	10/05/2013
	Communications Regarding Serious Incident Inquiry Report prepared by Cambridge University Hospitals NHS Foundation Trust (Addenbrooke's)	10/01/2014 - 05/02/2014
8	Communications with NNCCG concerning the preparation of an "independent" professional opinion by Dr Christine Vize.	2014
9	"Independent Professional Opinion" commissioned by NNCCG contrary to the wishes of the Hart Family. Author: Dr Christine Vize, Consultant Psychiatrist	13/07/2014 Received: 28/07/2014
10	Service Structures for the Norfolk Community Eating Disorder Service in September 2012, November 2012 and July 2013 Draft Service Specification for the NCEDS Service Care Programme Approach (CPA) Policy (CPFT)	09/2012 – 07/203 2010 2008
11	Notes from a Meeting with NNCCG dated 17th May 2013, discussing supervision arrangements with regard to CPFT.	17/05/2013
12	Medical Records for Averil Hart, as edited by Jane Shapleske, received after a request in 2013.	19/09/2011 – 15/12/2012
13	Averil's full medical records, received after a further request made in August 2014.	Not yet available, notes will follow as soon as possible.
14	Selected Research Papers / Journal Articles on Anorexia	Various
15	Extracts from the diary of Averil Hart, written during the course of her treatment at UEA.	08/2012 – 12/2012

16	Our complaint about Averil's transitional care, submitted to Cambridge and Peterborough NHS Foundation Trust	11/04/2014
17	Cambridge and Peterborough NHS Foundation Trust's reply to our complaint, signed by Aidan Thomas	22/05/2014
18	Averil's Medical Records as kept at UEA Medical Centre	27/09/2012 – 11/04/2013
19	Our complaint about Averil's care at UEA Medical Centre, submitted to NHS England	29/11/2013
20	Summary Document detailing our complaint, prepared by Diane Gypps (NHS England East Anglia).	16/12/2013
21	Communications with NHS England regarding our complaint about Averil's care at UEA Medical Centre.	30/11/2013 – 10/01/2014
22	Our complaint about Averil's care received at Norwich and Norfolk University Hospital.	09/01/2014
23	Response and Communications regarding our complaint to Norwich and Norfolk University Hospital.	16/01/2014 – 14/02/2014
24	Medical Review and Report prepared by Prof. Alastair Forbes on 05/03/2014 discussing Averil's care at NNUH.	05/03/2014
25	Subsequent communication regarding our complaint and the agreement of NNUH to hold a review with Paul Robinson.	
26	Our complaint about Averil's care received at Addenbrooke's Hospital, submitted 09/01/2014.	09/01/2014
27	Response and Communications regarding our complaint to Addenbrooke's Hospital.	05/02/2014
28	Notes from a meeting with Carol Miles, cleaner at UEA, who saw Averil on an almost daily basis.	03/01/2013
29	Clinical guidelines on Anorexia Nervosa: - MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa. - King's College Guidelines: A Guide to the Medical Risk Assessment for Eating Disorders	 2010 2009
30	E-mail by Dr Serfontein (via EDSIG) about Primary Care	27/01/2014
31	E-mails received from others treated at AEDS/NCEDS.	05/2014 – 06/2014