[AAAA]

DOB –

Appeal against Withdrawal of Continuing Healthcare Funding

[Date]

Contact:

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Introduction

Background

[AAAA] was initially assessed by the Continuing Healthcare Team (CHT) on the [xxx].

The assessment was conducted with the highest degree of compassion, professionalism and rigour.

We were briefed thoroughly regarding the process and were, at all times, included in each relevant step. Our views were actively sought and every attempt made to ensure that all aspects of [AAAA's] condition was communicated, document and understood.

We were left, by the end of the assessment, with a very high regard for the CHT team. It managed that very rare trick of holding [AAAA] and her needs at the centre of their thinking whilst still managing rigorously to discharge their legal and professional obligations.

The CHT provided a model of best practice for which we were very grateful.

The second assessment, conducted on the [xxx], was the polar opposite of the first.

Reasons for Appeal

There are two reasons for appeal: 1) Poorly conducted assessment process, which led to 2) Defective assessment of some Care Domains.

Poorly Conducted Assessment Process

Conduct of the assessment may be summarised as follows:

- No process briefing was offered or attempted.
- On the assessment day the Assessor was scheduled to arrive at 10:30. She actually arrived at 08:30 and attempted to interview [Dementia Lead Nurse] while she was dispensing medication.
- [Dementia Lead Nurse] spent ten minutes with the Assessor. The only subject discussed was [AAAA's] medication.
- Throughout the assessment the Assessor has attributed comments, including in some cases agreement to recommendations, to [Dementia Lead Nurse] none of which are true. [Dementia Lead Nurse] upon reading the assessment for the first time said:

  "I am very shocked at that report. Very untrue things. I was unable to spend time with her (the Assessor) as she came in at the wrong time and I was busy with medication rounds. I spent 10 mins with her".

- When we arrived we found the Assessor interviewing [AAAA] on her own.
- Our interview with the Assessor may be summarised as:
  - Brief and superficial
  - There was no detailed, line by line, discussion for each Care Domain i.e. no rigour.
  - [Dementia Lead Nurse] was not permitted to attend the review even though we wished her to be there.

  - [AAAA] remained with us during the whole interview. We contrast this with the first assessment where the Assessor ensured that [AAAA] was cared for away from the interview. This allowed us to speak more freely without her in the room. During the second assessment we felt the Assessor to be discourteous to [AAAA] by having her remain in the interview and this very much inhibited our exchanges with the Assessor.
  - The Assessor talked 'at us' rather than 'to us' and eye contact was avoided.
  - The interview was devoid of any compassion, professionalism or rigour.
  - The interview took approximately twenty minutes. We contrast this with our interview as part of the original assessment which took over three hours.
- The results of the assessment were not discussed with us.
- The decision to withdraw funding and the associated reasons were not discussed with us.
- We discovered that funding was to be withdrawn only when we received a telephone call from the County Council that was enquiring about [AAAA's] financial position.
- It took several phone conversations and emails before a copy of the assessment together with a letter informing us of funding withdrawal was actually received.

Defective assessment of some Care Domains

We believe that the Care Domains of **Mobility, Nutrition** and **Continence** were incorrectly assessed.

All three Domains have been downgraded which implies either an improvement in [AAAA's] condition and/or a lessening of risk. Our own observations suggest that, far from improving or even remaining stable, [AAAA's] condition is actually worsening.

We discuss each downgraded Care Domain below.

1. Mobility

Previously rated as **Moderate**, this has now been downgraded to **No Needs**.

a. Previous assessment:

"Evidence indicates a **Moderate Need**. [AAAA] is independently mobile but can be unsteady at times. There is evidence to suggest that she has had two possible unwitnessed falls during the assessed period. [AAAA] does not have any muscle spasms or contractures."

"[AAAA] occasionally uses a folding frame wheelchair to move around and may require some guidance".

b. Current Assessment

"Assessed as **No Needs. [AAAA]** is independently mobile but is unaware of her surroundings and will walk into furniture so she requires monitoring whenever she is walking about. She has not had any recent falls".

i. [Senior Nursing Home Nurse] (but ***NOT*** [Dementia Lead Nurse] as stated in the assessment):

"[AAAA] is independently mobile, does not need any equipment and has not had any falls since the initial assessment. She is not aware of her surroundings though, and has walked into furniture ***so is at risk of falls***."

ii. "The level of need was discussed with the RN in light of evidence and she agreed that a rating of **No Needs** would support [AAAA's] level of need within this domain".

c. Is this Assessment Correct?

The following observations are relevant:

i. [Senior Nursing Home Nurse] (but ***NOT*** [Dementia Lead Nurse] as stated in the assessment) state, at 1b i), that [AAAA] "…is at risk of Falls".

We know that the attribution of agreement to [Dementia Lead Nurse] is untrue since the issue was never discussed.

We also know that In a subsequent discussion with [Dementia Lead Nurse], she stated that the Risk Plan was up to date and, in her view contained the correct rating i.e. Fall Risk – High Needs

Logically, if [AAAA] is at risk of falling, then the rating cannot be No Needs since this suggests the 'falling risk' requires no management which clearly cannot be correct.

ii. Although occurring shortly after the assessment, [AAAA] suffered a fall that required hospitalisation. In addition, there have been numerous occasions where we have had to catch [AAAA] when she has lost her balance or supported her when moving around and, in our experience, these occasions are increasing.

iii. [Senior Nursing Home Nurse] (but ***NOT*** [Dementia Lead Nurse] state at 1 b i) that [AAAA] no longer needs aids to walk about.

We believe that [AAAA] no longer attempts to use walking aids because she no longer has the mental ability to understand what a walking aid might be or from where she might obtain one. Again, more rigour in the assessment would have allowed this issue to be fully considered.

iv. If [AAAA's] assessed need is to be downgraded from Moderate to No Needs then, by definition, there should be a clear improvement in her Mobility. The actual evidence would suggest that the risk of falling has, as a minimum, ***not diminished*** and could, in fact, be increasing which is why [Dementia Lead Nurse] assessed [AAAA] as requiring **High Needs**.

Given the observations above, it is difficult to see how [AAAA's] mobility has ***improved*** to a point which could justify a downgrading from **Moderate Needs** to **No Needs**.

The Care File / Risk Assessment places [AAAA] at **High Risk**. We believe this to be the minimum rating for this Care Domain. We spend a lot of time with [AAAA] and would therefore go further and say that ***Care staff are unaware*** of a great many occasions when [AAAA] either has needed support to move around or has been saved from injury when we have caught her in the act of falling. [AAAA's] condition is worsening and we believe that it will not be many weeks before a strong case for a rating of Severe Needs can be made.

2. Nutrition

Previously rated as **High** this has now been downgraded to **Low**.

a. Previous Assessment

Evidence indicates a **High Need**. [AAAA's] nutritional status is at risk. Her appetite is poor and variable and she has lost weight since her admission. Verbal evidence suggests that she was a size 16 and is now a size 8. She has lost 3kg in 12 weeks.

Her meals are fortified and concerns have been raised with the GP. However, a referral to a Dietician has not been made and supplements have been prescribed. [AAAA] is now being weighed weekly.

[AAAA] does require encouragement to eat. Snacks are provided in between meals. Food needs to be cut up and [AAAA] can feed herself with a fork and spoon but cannot coordinate to use a knife and fork.

When HCM met [AAAA] she looked very thin and undernourished.

b. Current Assessment

Assessed as **Low Needs.**

[AAAA's] weight has stabilised and has been maintained since the initial assessment. Her BMI is within normal range. Her dementia impacts her ability to ensure she takes sufficient nutrition requiring staff to monitor, supervise and encourage her to eat and she is given fortified meals and snacks throughout the day.

i. [Senior Nursing Home Nurse] (but ***NOT*** [Dementia Lead Nurse]

[AAAA] has maintained a steady weight since January this year. She has lost weight in the past but her BMI is now within normal range. She receives a fortified diet and requires encouragement and monitoring by staff to ensure that she completes her meals. Her dementia impacts on this and she grazes all day and snacks rather than eats a full meal at any one time.

ii. [AAAA]

Mr [AAAA] stated that he usually eats a meal with his wife as she eats better if there is someone with her. Sometimes she refuses to eat and it seems that she can go on for a couple of days like that. Her coordination using a knife and fork is deteriorating and she needs her food cut up. Family are unsure if [AAAA] eats the snacks that are left out for her as she may not see it or think to help herself.

c. Is This Assessment Correct?

The following observations are relevant:

i. [Senior Nursing Home Nurse] (but ***NOT*** [Dementia Lead Nurse] said at 2 b i) that "[AAAA] has maintained a *steady weight* since January this year".

In fact, [AAAA's] Weight Monitoring Sheet shows, for the period January 2016 through November 2016, a weight variance of 5kg (51kg – 46kg).

ii. Could there be a failure of logic in this assessment?

Notwithstanding [AAAA's] *variable* weight, the logic of moving from a High to Low assessment seems to rest on the fact that [AAAA] has gained weight in the last four months.

As we understand it, the Continuing Healthcare assessment is focused upon [AAAA]'s ***healthcare*** needs i.e. the extent and nature of nursing inputs (as distinct from *Social Care* inputs) required to achieve the desired patient outcome.

So – [AAAA]'s weight did not magically increase of its own accord. It increased because of the *sustained* Nursing interventions applied.

No evidence has been provided to suggest that the requirements for nursing interventions have reduced – merely that [AAAA]'s weight has increased - ergo the stability of [AAAA]'s weight depends upon a sustained level of nursing inputs.

It is reasonable to argue therefore that if the nursing interventions were reduced, we could reasonably expect [AAAA]'s weight to decline over time.

iii. [AAAA]'s willingness and ability to consume any form of nourishment is declining. She will not eat unless directly fed. On many occasions we are unable to get her to eat and it requires a nurse with formal dementia training to gain her cooperation.

In our view, [AAAA]'s willingness to cooperate is getting worse – it is certainly not improving. If [AAAA]'s ability to eat has not improved, then what would be the justification for a reduction in rating from **High Needs** to **Low Needs?**

3. **Continence**

Previously rated as **Moderate** this has now been downgraded to **Low**

a. Previous Assessment

Evidence indicates a **Moderate Need**.

[AAAA] does have frequent urinary tract infections and written evidence does suggest that she has had them monthly since April. Verbal evidence suggests that [AAAA] was able to recognize when she required the toilet in April and the plan indicates occasional incontinence. Since May verbal evidence indicates that she has been doubly incontinent.

Comments from RNMH (MDT) and [Dementia Lead Nurse]

In April [AAAA] had little accidents and would recognise when she needed to go to the toilet. From May onwards she has been doubly incontinent. A laxative is prescribed PRN. [AAAA] has had quite a few urinary tract infections – almost monthly. She needs to drink more but it is often difficult to get her to drink.

b. Current Assessment

Assessed as **Low Needs**.

[AAAA] is continent of urine and faeces but requires assistance to locate the toilet and with hygiene and pads. She has had urinary infections which impact on her behaviour but none in the last three months. Her skin condition – Lichen sclerosis – impacts on her behaviour.

i. [Senior Nursing Home Nurse] (but ***NOT*** [Dementia Lead Nurse] as stated

[AAAA] has had frequent urinary tract infections - treated with antibiotics – and which impact on her behaviour as she cannot sit still.

Her skin condition of lichen sclerosis impacts on her continence. She has not had a UTI for the last 3 months. She is continent of faeces with support.

ii. Mr [AAAA]

[AAAA] is incontinent now and family note that she has not had a urinary tract infection for 3 months.

iii. [Dementia Lead Nurse] – Conversation with Mr [AAAA] ***after*** Assessment

"[AAAA] is doubly incontinent. She is unable to say when needing the toilet. She continues to have urinary infections".

iv. Risk Assessment Plan as prepared by [Dementia Lead Nurse] (page 15)

Continence rated as **Moderate Risk** within the Risk Plan

Urinary Continence

- [AAAA] has frequent or more severe urine incontinence difficulties
- [AAAA] is often incontinent of urine both day and night
- Continence pads required
- Encouraged to use the toilet regularly but refuses

Bowel Continence

- [AAAA] has occasional continence difficulties during day or night
- She can occasionally experience diarrhoea
- Requires disposable pads
- May need a carer to remove / lift clothing when using the toilet or commode
- Needs to be reminded to go to the toilet frequently throughout the day

c. Is this Assessment Correct?

i. The evidence provided for the assessment of Continence is clearly conflicted.

Comments from [Senior Nursing Home Nurse] (but ***NOT*** [Dementia Lead Nurse] at 3 b i) suggest that [AAAA] is continent of faeces ***with support***. Though not explicitly stated they imply an incontinence of urine.

Mr [AAAA] at 3.b.ii) states clearly that [AAAA] is incontinent but it is not clear from the Assessor's note whether they mean doubly incontinent or incontinent of urine.

[Dementia Lead Nurse]at 3.b.iii) clearly states, in a conversation with Mr [AAAA] after the assessment, that [AAAA] is doubly incontinent and continues to have urinary infections.

The assessor states that "[AAAA] is ***continent*** of urine and faeces".

It would appear that the evidence from Mr [AAAA], [Dementia Lead Nurse] and the Care File / Risk Assessment conflicts with the recorded view and notes of the Assessor. Only the Assessor can explain why this might be.

Given the diversity of views expressed, it is self-evidently the case that no firm conclusions can be drawn from this evidence save that [AAAA] has an incontinence problem of some kind that requires nursing interventions.

ii. The current assessment states that [AAAA] "…has urinary infections which impact on her behaviour *but none in the last three months*. Her skin condition – Lichen sclerosis – impacts on her behaviour".

We have no clinical training and are not expert in the management of Dementia. We are, however, experts on the subject of '[AAAA]'.

We know that her behavioural changes usually correlate with urinary infections. There have been many occasions when we have had to ask for either a test for urinary infection or for antibiotics to be administered. The implication of this is that the early stages of urinary infection are not always noticed by those staff that are not in regular contact with [AAAA].

This means that the infection can become more severe than might otherwise be the case. By way of example, no infections were reported within the days prior to [AAAA]'s hospitalisation resulting from a fall. However, the hospital reported that [AAAA] had been admitted ***with*** a urinary infection.

iii. As [AAAA]'s mental condition declines, her ability to comprehend any notion of cleanliness, toileting or hygiene have evaporated. Her skin condition and frequent urinary infections changes her behaviour. She becomes very aggressive and, increasingly now, has become a risk to herself and others. More specifically, her ability and willingness to cooperate when cleaning up have become very difficult.

[AAAA's daughter] – "A while ago, Mum would let me shower her and/or clean her up when she had her 'accidents'. Now she will not cooperate with me in any way and I have to rely on a properly trained nurse to win her cooperation which may take some considerable time. There is no doubt in my mind that the problems associated with Continence are getting worse but there was no opportunity to discuss this with the Assessor".

iv. If [AAAA]'s assessed need is to be downgraded from Moderate to Low then, by definition, there should be a clear ***improvement*** in her Continence.

The actual evidence is clearly conflicted but in our minds, we are clear that the risks associated with the Continence Care Domain have, as a minimum, ***not diminished*** and, in fact, are increasing.

v. Given the current state of evidence as reported in the assessment, it is impossible to rate this issue and it therefore requires a reassessment.

Conclusion

We believe that our observations set out above clearly demonstrate a lack of compassion, professionalism and rigour in the conduct of the Assessment and that this has led to incorrect ratings for the Care Domains of **Mobility, Nutrition** and **Continence**.

We therefore request a reassessment. In so doing, we acknowledge the very real constraints and financial pressures under which the CHT must work.

Notwithstanding the problems associated with the assessment as discussed above, our confidence in the professionalism of the CHT remains high and we hope that it will grant us an opportunity properly to assess [AAAA]'s needs as it did in the first assessment.

Ends.