North Tyneside and Northumberland Safeguarding Adults Board

# LEIGH

## A Safeguarding Adults Review (SAR)

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## 1. INTRODUCTION

1.1. A referral for a SAR was received by N&NTSAB in respect of Leigh. The circumstances related to the referral were that Leigh had a history of psychosis, substance misuse and was HIV positive. Leigh was not able to engage with all treatment, care and support and was admitted to hospital due to the effects of severe self-neglect, including dehydration and emaciation due to complications of her untreated HIV infection.

1.2. Leigh was eligible for s.117[1] aftercare following discharge from detention under s.3 of the Mental Health Act nine months previously.

1.3. Leigh died in hospital aged 38 years. The cause of death was recorded as associated with complications from HIV. Allegations of exploitation against her friend with whom she was staying before hospital admission and against her daughter were investigated but no crime was found to have been committed.

1.4. More details regarding Leigh as a person, her background and how she came to find herself in the situation that led to her untimely death, all form part of this report.

## 2. PROCESS AND SCOPE

2.1. The Terms of Reference and details regarding the methodology used for the SAR can be found in Appendix 1. These were amended following restrictions placed on agencies due to the Covid-19 pandemic response; the proposed methodology was changed after a period of inactivity with the review to include a series of learning and reflection workshops conducted using virtual meeting technology.

2.2. The review will cover a year prior to the death of Leigh.

2.3. For the purposes of this review reference will be made to geographical areas as follows:

| Area 1 (Area of Residence) | Area 2 (Larger local City) |
|---|---|

2.4. There were three HIV services supporting Leigh. For ease of reference these will be referred to as follows:

| Service | Referred to as |
|---|---|
| Local HIV Service NHS Hospital Trust Area 1 | Area 1 NHS HIV Service |
| Regional Specialist HIV Service NHS Hospital Trust | Area 2 NHS HIV Service |
| Charitable Trust HIV support service | CT HIV Service |

## 3. THE REVIEWER

3.1. North Tyneside Council, on behalf of the N&NTSAB, commissioned an independent reviewer to chair and author this SAR. Karen Rees is an Independent Safeguarding Consultant with a nursing background. Karen

[1] **Section 117 aftercare** is a legal duty that is placed on health and social services to provide after care services for individuals who have been detained under Section 3, Section 37, Section 47, Section 48 and Section 45A. It is the duty that comes in effect once the person has been discharged from the hospital. The aim of Section 117 aftercare is to provide services to prevent further admissions to a hospital. Section 117 aftercare is normally arranged by the care co-ordinator however, it is a multi-disciplinary and multi-agency responsibility.

worked in safeguarding roles in the NHS for a number of years. Karen is completely independent of N&NTSAB and its partner agencies.

## 4. FAMILY INVOLVEMNT IN THE REVIEW

4.1. Contact was made with Leigh's family to invite them to be involved in the review. One of Leigh's eldest daughters and Leigh's youngest sister spoke with the author prior to the workshops. Their views and information are included in the review and feedback on the findings was given. Much of the history that brings an understanding to the person that Leigh was, came from her sister. Some of this information has been withheld from this report but has helped the review understand more about the difficulties and challenges that Leigh experienced.

## 5. LEIGH and RELEVANT HISTORY

5.1. Leigh was of White British origin and previously lived in another area of the country. Her life was lived within a culture of violence including domestic abuse[2] from her own experiences in childhood through to her adult relationships. Leigh spent some time in local authority care as a teenager. Leigh started using cannabis at age 13, given to her by her parents as a way of keeping her calm. Leigh continued to use cannabis, stating it was the only medication that she needed.

5.2. It was in the last relationship before Leigh, moved into the area, six years prior to the review period, that Leigh became infected with HIV. Leigh's then husband had HIV but did not inform her of this. This relationship was significantly violent, resulted in Leigh becoming infected and included a period where Leigh was held prisoner by him.

5.3. Leigh had five children from three of her violent relationships. Leigh and her five children were rehoused in a refuge in Area 1 as a result of fears for her safety when her ex-husband was released from prison. The eldest two were twin girls who Leigh continued to have a relationship with until she died.

5.4. Leigh continued to experience violent relationships when she moved to Area 1. Aggression was also a feature of how the family resolved difficulties when Leigh lived with her eldest children. Leigh engaged with children's social care and worked hard over a long period to retain residency of her younger children which had been successful.

5.5. Leigh was not prescribed treatment for her HIV; the reasons for this are complex and are discussed within this report. Leigh was, however, in contact and supported by specialist HIV services in the region that she lived albeit this engagement was spasmodic.

5.6. Leigh first came to the attention of mental health services nine months prior to the start of the scoping period. This appeared to be due to drug induced psychosis. During this time Leigh was admitted to hospital on several occasions and was detained under section 2 of the Mental Health Act. When Leigh became

[2] **The Home Office** defines **domestic violence and abuse** as: "Any incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse between those aged 16 or over who are or have been intimate partners or family members regardless of gender or sexuality. This can encompass but is not limited to the following types of abuse: psychological; physical, sexual, financial and emotional."

mentally unwell, children's social care placed the three younger children with identified family that could care for them. During the review process, information regarding this was sought following findings of the impact that this had on Leigh. The review was informed that the children's fathers shared parental responsibility with Leigh. Police checks were undertaken that did not flag anything of concern and so the youngest three children moved to live with their respective fathers. Leigh was prevented from having a relationship with them after that point although it is not known how or why this happened.

5.7. During her third admission there were risks identified to herself and others. A safeguarding referral was made in respect of Leigh's older children regarding any risk that she may pose and that they may have needs as carers if they were caring for their mother when she was presenting as psychotic. Workers involved in this review are not aware of the outcome of this referral and it is outside the timeframe of this review.

5.8. It was noted that Leigh had particular issues with her neighbours. Leigh also experienced housing issues in that there were rent arrears, the boiler was not working and there were various other repairs required to the property. Support was in place to manage these issues via the discharge plan by the services involved with her and neighbourhood police.

5.9. Leigh requested to move to a smaller property and away from the neighbourhood. This had not been possible. As the discharge was approaching housing services stated that they were unable to carry out the necessary cleaning and maintenance within the required timeframe prior to Leigh's return. It is noted that a discharge meeting had taken place where the general opinion was that Leigh was ready to be discharged as the psychosis had been drug induced and did not therefore require further mental health treatment. Notes at the time suggested that Leigh insisted on being discharged. Leigh indicated to some professionals that she felt that she could no longer stay in hospital having been informed that she could not refuse to be discharged. Leigh discharged herself before the date that had been planned, returning to a property that was not in a habitable state. This discharge happened four months prior to the review period. Leigh had an appointment at the substance misuse service; she attended one appointment but did not attend any more and was discharged. Leigh continued to use cannabis regularly.

5.10. Two months following discharge, a safeguarding alert was raised by the health psychologist[3] within the Area 2 hospital who was working closely with the NHS HIV Service and is discussed in section 7 of this report due to its relevance to the time period of the review.

5.11. It is important to note that despite the challenges that Leigh had faced in her life, and the trauma she experienced, she was highly respected by many of those that worked with her for her ability to care for her children, and for the attempts she made to make changes in her life. Her family described her as a very caring person who would do anything for anyone. Her younger sisters described her as a mother to them during their difficult childhood. Two years before Leigh's first admission under the Mental Health Act, Leigh enrolled on a college course in construction. Leigh did well, was student president and awarded student of the year the following year. Leigh's sister told the author that she flourished during this time. One of the

[3] **Health psychologists** are specially trained to help people deal with the psychological and emotional aspects of health and illness as well as supporting people who are chronically ill
https://www.healthcareers.nhs.uk/explore-roles/psychological-therapies/roles/health-psychologist

professionals told the author that Leigh was a remarkable woman who, at times, achieved against the odds. Another professional described Leigh as 'resilient and resourceful'. This report and the learning will recognise the contrast to the character that was seen during the time period of the review, the impact of the significant trauma experienced by Leigh throughout her life, particularly after the younger three children went to live with their respective fathers.

## 6. LEIGH KEY EVENTS/TIMELINE

6.1. The following represents a short summary of the key events in each phase of the time period under review. This will inform the areas for in depth exploration and analysis in section seven of this report.

### Key Phase One- Admission to Mental Health Ward- Discharge (9 1/2 weeks)

6.2. Leigh had been displaying some behaviours in the recent weeks that had caused concern to her CT HIV Service support worker. The HIV support worker contacted the mental health services who triaged Leigh over the phone a day later. The delay is subject to further comment in section seven. No concerns were evident to the mental health team on talking with Leigh.

6.3. Four days later, a member of the public rang the police concerned for Leigh's wellbeing. Police located Leigh and the street triage team[4] were called; Leigh was detained on a Section 136 Mental Health Act[5] and assessed by the mental health team. Leigh was detained under section 2[6] for further assessment and then Section 3 for treatment. Previous admissions and diagnoses of drug induced psychosis were noted.

6.4. During the admission mental health staff on the ward contacted the Area 1 NHS HIV service and advice was received and followed regarding Leigh's HIV treatment. It was established that Leigh was not prescribed or taking any treatment for her HIV but that her HIV and other blood tests did not show concerns and should continue to be monitored. The CT HIV Service support worker and the health psychologist from Area 2 were not alerted to the admission and were trying to locate and engage with Leigh during this time.

6.5. Leigh's behaviour presentation and psychosis did not improve once she was an inpatient and no longer taking illicit substances; Leigh was commenced on antipsychotic medication via depot injection[7] and her

[4] [4] **The street triage teams** consist of nurses and local police forces to reduce the number of inappropriate detentions made under Section 136 of the Mental Health Act (MHA) and to make sure that people who need mental health treatment receive it as quickly as possible. They work seven days a week to ensure those who come into contact with the police receive a high quality, effective service and are able to signpost to support services.

[5] **Section 136** gives the police the power to remove a person from a public place, when they appear to be suffering from a mental disorder, to a place of safety. The person will be deemed by the police to be in immediate need of care and control as their behaviour is of concern. It is important to point out that a person is not under arrest when the decision is made to remove the person to a place of safety. The police power is to facilitate assessment of their health and wellbeing as well as the safety of other people around them. The person will then be assessed by an approved mental health practitioner and a doctor.

[6] **Section 2** is part of the civil **sections** under the **Mental Health Act (1983)**. It provides for someone to be detained in hospital under a legal framework for an assessment and treatment of their **mental disorder for up to 28 days**. **Section 3** of the **Mental Health Act** is commonly known as "treatment order" it allows for the detention of the service user for treatment in the hospital based on certain criteria and conditions being met.

[7] A **depot injection** is a slow-release form of antipsychotic medication. It's the same medication as the antipsychotic that comes in tablet or liquid form. But it is given as an injection in a liquid that releases it slowly, so it lasts a lot longer.

psychotic presentation started to improve.

6.6. It was noted that the housing situation from the previous admission had not improved; referrals were made to Adult Social Care Mental Health Team and Mental Health Reablement Team who were to work with Leigh towards finding suitable housing, resolving rent arrears and enabling support for Leigh on discharge. During admission the Mental Health Trust Occupational therapist also worked to secure repairs to the property secure and source a suitable new tenancy. Leigh was also reluctant to return to the property that she currently had the tenancy for, due to significant neighbour issues. The Adult Social Care Social Worker (ASC SW) was also appointed as Leigh's Care Programme Approach[8] care coordinator.

6.7. Following Leigh's section 3 Mental Health Act detention being rescinded, a multi-disciplinary discharge planning meeting was held. Leigh was fit for discharge and was not able to remain an inpatient purely because of housing issues. Plans were made in agreement with Leigh, that an application for housing closer to the large specialist hospital in Area 2 where she could attend for her HIV treatment would be made. Leigh agreed to discharge to her previous property whilst she was supported to identify accommodation in Area 2.

**Key Phase Two- the six months post discharge.**

6.8. Following discharge Leigh was followed up by the Mental Health Trust community team as is a requirement of the Mental Health Act and expected practice. There were no concerns and Leigh was discharged from that service.

6.9. During this phase the ASC SW and Community Psychiatric Nurses from the depot clinic, ensured that Leigh was enabled to attend her depot clinic appointments so that she could receive her medication regularly. Although there were occasional appointments not attended, on the whole, Leigh did get her injections albeit maybe not always on the day they were due. Leigh's mental health remained stable.

6.10. The mental health reablement service continued to work with Leigh on resolving housing and rent arears issues. Leigh did not stay at her house on discharge, she went to stay with a friend. One of Leigh's daughters also stayed there. Although it had been agreed that a move to Area 2 would be beneficial for Leigh's contact and support regarding her HIV, housing officials identified that this would not possible due to Leigh having no local connection to that area. Leigh was granted the tenancy of a new build flat in Area 1, two months after discharge. Although Leigh accepted the property she only stayed there on a couple of occasions as she wanted to remain living in the company of her friend and daughter.

6.11. During this phase, Leigh did not attend most of her HIV follow up appointments. The discharge plan had been for careful monitoring of Leigh's blood to ensure that her HIV remained stable despite not having treatment.

6.12. The CT HIV Support Worker went on a period of leave within this period. It had been agreed that there would be no benefit of introducing a new worker due to AC's current mental state, and as there were now

[8] **The Care Programme Approach (CPA)** is a way that services are assessed, planned, coordinated and reviewed for someone with mental health problems or a range of related complex needs. http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/care-programme-approach.aspxteh

several services supporting Leigh.

6.13. Both the ASC SW and the mental health reablement officer, were trying to support Leigh to register with a new GP in this phase, given that she had changed address (the new flat). There is no record that Leigh was ever registered with a new GP.

6.14. The mental health reablement officer ended their involvement at this point.

6.15. It was noted that Leigh was neglecting her personal care in this phase. Those who attended the workshops and knew Leigh, said that she often presented as dishevelled and slightly unkempt in this period. Leigh's mental health remained stable.

### Key Phase Three- The fifteen weeks until Leigh died

6.16. Leigh's presentation changed in this period. In a visit to her friend's home by ASC SW, Leigh was still in bed. She appeared confused and thought that the ASC SW was there to take her to an appointment. ASC SW was making an unannounced visit to see how Leigh was managing. Leigh's friend told the ASC SW that Leigh had a fit a couple of weeks previously. Leigh stated that she was having dizzy spells, was unsteady on her feet and sleeping a lot. A plan was made for Leigh to make a GP appointment for when she attended her depot appointment in a couple of days. There is no evidence that Leigh attended the GP and did not attend the depot appointment.

6.17. Nine days after the social work visit, Leigh attended a mental health outpatient clinic. Leigh arrived in a taxi with her daughter. ASC SW also attended the appointment. The doctor who reviewed Leigh was very concerned regarding her physical appearance. As well as what the ASC SW had been told at the previous visit, it was noted that Leigh had dirt on her face and arms, a skin infection on her face, bad odour, not eating well, not able to handle things with her hands and was pacing throughout the appointment.

6.18. The doctor was very concerned about Leigh's symptoms, given Leigh's HIV diagnosis. It was agreed that Leigh would attend the NHS walk in centre at the local hospital with a letter from the doctor, make an appointment with the GP as soon as possible and start engaging with the HIV services. The new GP was informed of the clinic attendance. The new practice had no record of Leigh so returned the letter; it was later identified that Leigh was still registered with the previous practice.

6.19. Four days later Leigh's friend contacted the ASC SW to say that they had been to the hospital for blood tests but that the hospital was not able to undertake the tests. ASC SW phoned the friend back and stated the importance of Leigh seeing her GP as soon as possible.

6.20. Nine days later, ASC SW called unannounced at Leigh's friend's house. ASC SW did not see Leigh as she was asleep. Her friend stated that she had not seen the GP. ASC SW contacted the mental health doctor to discuss Leigh's ongoing depot injections. It was agreed that these would not be given until Leigh's physical health care issues had been assessed. An urgent appointment was made for a health assessment at the mental health trust for five days later. The ASC SW delivered the appointment, the door was opened but closed again, the ASC SW knocked but there was no further answer; the ASC SW posted the appointment

letter through the door.

6.21. Leigh attended the appointment alone and was seen for an annual health review assessment by the physical health lead at the Mental Health Trust. Leigh appeared to be the same as seen at the previous appointment but was only able to answer a few questions. Leigh had bloods taken (not for HIV markers), alerts were raised for liver function and cholesterol. Leigh's blood pressure was noted to be low, and pulse was high. Leigh was given a form to go to the hospital for an electrocardiogram.

6.22. Three days later the Community Psychiatric Nurse (CPN) and ASC SW accompanied Leigh for her depot injection. She remained looking very unkempt and although engaged in conversation, she was slow to respond. Leigh stated that she had no issues at that time.

6.23. Two weeks later records show that the Area 2 NHS HIV Service and the health psychologist in Area 2 were concerned that they had not seen Leigh for a while. Contact was made with the Area 1 NHS HIV Service. The psychologist sent an email to ASC SW with an appointment to attend for an HIV outpatient's appointment in Area 2 or if Leigh did not want to do that then she should attend the HIV centre in Area 1.

6.24. Two days later Leigh was accompanied to her depot appointment, it was noted that she continued to be in an extremely neglected state, was unsteady on her feet and stated that she felt dizzy. Leigh accepted the appointment for the HIV clinic at Area 2 hospital.

6.25. Two weeks later, ASC SW contacted Leigh to remind her about an outpatient appointment that had been arranged for the following week. As there was no answer, the ASC SW contacted Leigh's friend. The friend agreed to support Leigh to attend the mental health outpatient appointment as well as the HIV clinic appointment the day after. During this call, Leigh's friend told the ASC SW that Leigh's health had deteriorated further indicating significant concern for her welfare. ASC SW strongly advised Leigh's friend to call 999. The friend stated that she would see how she was over the next 24 hours and then make a decision.

6.26. The ASC SW was very concerned and sought support from the team manager. The social worker recorded that there was a plan to arrange a S117/CPA review and that Leigh had a couple of appointments over the next week that the friend said she would support with. The discussion with the manager is not recorded.

6.27. The next day (non-working day) ASC SW contacted the Emergency Duty Team to discuss the concerns. The Emergency Duty Team tried three times to contact Leigh but could get no answer. ASC SW was contacted with information related to the failed attempts to make contact. ASC SW stated that they would pick it up the next working day.

6.28. ASC SW was not at work on the next working day so asked the Mental Health Trust community team for an urgent visit as there were concerns for the welfare of Leigh. The Mental Health Trust community team visited Leigh, but her friend would not allow access stating that Leigh was sleeping, that they had called an ambulance and were waiting for it to arrive.

6.29. Leigh's daughter contacted her own leaving care social worker about her concerns for her mother. After several phone calls and on hearing that the Mental Health Trust community team had already been to see

Leigh and not gained entry to the house, the leaving care social worker went to see Leigh. The leaving care social worker was allowed access as she knew the family and had a good relationship with the daughter. On seeing the very neglected and grave state that Leigh was in, the leaving care worker called an ambulance.

6.30. Safeguarding referrals in respect of self-neglect were made by the Ambulance Service, ASC SW and the Accident and Emergency Department the same day and by the leaving care worker and the Acute Hospital ward the following day.

6.31. Leigh remained in the local general hospital for three days where it was discovered that Leigh's HIV condition had deteriorated, and she had progressed to Acquired Immune Deficiency Syndrome (AIDS). Leigh was transferred to the local specialist hospital in Area 2. Leigh initially improved but then deteriorated and died. Leigh's cause of death was progressive multifocal leukoencephalopathy[9] a serious and now very rare AIDS defining Illness (see appendix 2) as a complication of untreated HIV. During Leigh's admission, family members raised concerns regarding money missing from Leigh's bank account and the care she had received at her friend's house. Safeguarding referrals were made and investigations commenced. Leigh died the day after the safeguarding meeting. No evidence of any criminal activity had been found. A referral was made for this SAR.

## 7. AREAS FOR LEARNING AND IMPROVEMENT

7.1. The analysis section takes a strengths-based approach identifying what went well and then building a picture of areas where learning has occurred. Systems and services that worked with Leigh have been updated and improved since this case. This is due to natural ongoing improvement, service changes, and elements that have been changed already due to early learning from this review.

7.2. There are systems and processes that may have given more light to the fact that Leigh's HIV illness was progressing to a state that would become irreversible. The themed areas below were discussed in workshops each focussing on one theme. There were also some cross-cutting themes such as mental capacity that are addressed throughout the report.

### Assessment Care and Review

7.3. The first section of analysis identifies learning in respect of the delivery of care to Leigh for both her mental health and her physical health care needs.

7.4. A decision was made during this review process to look briefly at the previous period of admission to the Mental Health Trust described in section 5, as it is relevant to understand Leigh's mental health diagnosis and treatment at that point; it sets the scene for the period under review.

[9] PML stands for progressive multifocal leukoencephalopathy. It's a very rare aggressive viral disease of the central nervous system. The virus attacks cells that make myelin. Myelin is a fatty substance that coats and protects nerve fibres in the brain, which helps conduct electrical signals. PML can result in symptoms that affect virtually any part of the body. There is an increased risk of developing PML in those with have HIV-AIDS

7.5. Leigh had been admitted and diagnosed with a drug induced psychosis. Leigh was followed up by the Mental Health Trust community team on discharge and had agreed that she would engage with drug services. Leigh's engagement was not sustained with either of these services. The Mental Health Trust community team discharged Leigh 12 weeks later.

7.6. Concerns were expressed by the Area 1 and 2 NHS HIV services and the CT HIV support service due to Leigh's erratic presentation. On making contact with the Mental Health Trust community team, the CT HIV support worker was informed that they would take this forward, and no further action was required by the CT HIV support worker. It was noted that Leigh had been discharged from mental health services; this was not known to the CT HIV support worker. The CT HIV support worker missed a call back with a message left that the appropriate pathway would be through the crisis mental health team. The message stated that the community mental health team had informed the crisis team of this alert but would need to speak to the HIV support worker before they could progress the referral. The call between the CT HIV support worker and the crisis team was completed the day after the message was received hence the delay. The referral resulted in a triage call within four hours to Leigh. On the day that Leigh was contacted, she appeared to be very calm and not aware of the concerns of professionals. Leigh stated that she was not mentally unwell but just irritable and frustrated with her social circumstances and housing. Leigh was therefore not seen.

7.7. All of the services on this occasion responded appropriately and worked within their guideline's indicating strong practice. There did appear to be a lack of communication between services though, with the CT HIV service not having been notified of Leigh's discharge from mental health services. HIV services (CT and NHS Area 2) continued to be concerned about Leigh. It is possible that, based on the concerns that had been observed by a professional, a challenge to the decision not to see Leigh could have resulted in a review of the clinical decision by the mental health services. That is not to say that it would have resulted in a different outcome but does lead to learning that is similar to learning discussed throughout this report regarding the importance of professional challenge.

7.8. With Leigh's presentation continuing to be of concern, it was not long before Leigh was detained under a Section 136 of the Mental Health Act. This system worked well with police recognising the need to involve the Street Triage Team, resulting in Leigh being conveyed to a place of safety and being assessed and detained under the Mental Health Act. This provides evidence of strength in the system.

7.9. Once admitted to the mental health ward, HIV services, (both Area 1 NHS HIV service and the CT HIV Service) were trying to locate Leigh as she was not engaging with them. It is of note that this continued for a while after Leigh's admission. When this was discussed in the workshop, it was identified that it can be difficult for ward staff to understand exactly who is working with a person. It was identified that the ward will always contact the GP for information. It was noted that the GP can also be a source of information for who else might be working with a patient as it is usual to write to GPs to update them on progress with any service that a patient is being seen by. This has led to learning for all agencies.

7.10. As the mental health inpatient staff became concerned that Leigh's behaviour was not improving despite her not having access to any illicit drugs, treatment was commenced for psychosis of alternative cause. This was further evidence of continuing strong practice to identify the cause of Leigh's disruptive behaviour that was deemed to be putting, herself, other patients and staff at risk of harm. It is of

significant note that once Leigh had commenced on medication, her behaviour became stable, and she no longer displayed any psychotic symptoms. The diagnosis of drug induced psychosis during the previous admission was made based upon clinical presentation at the time; all evidence during that admission led the team at the time to formulate that diagnosis.

7.11. There was also good evidence of the consideration of offering Leigh continued care for her HIV whilst on the ward. There are records of conversations between the CT HIV Service support worker, the Area 1 NHS HIV service in Area 1 and the mental health ward. Leigh's blood tests indicated no immediate need for treatment for HIV (see appendix 2). It was noted by those caring for Leigh's HIV status that she was very aware that if she started on treatment for her HIV that she knew that she would have to take the medication at the same time of the day every day. To take it erratically would mean that the virus would mutate, treatment would be ineffective and would need changing. If this continued, then no treatment would be effective, and the virus would not be able to be stabilised.

7.12. The knowledge that Leigh had about her HIV status and treatment was further evidence of how well she was supported to understand her disease. Leigh always maintained that her lifestyle and personality would mean that she would not be able to comply to such a stringent treatment regime. It would, however, always be important for Leigh to engage with HIV services so that her blood levels could be assessed, her disease progression monitored and that she was able to manage emotionally with her condition.

7.13. Area 1 and 2 NHS HIV services were well set up to offer Leigh a service that fitted around her. It was agreed that she could attend Area 1 or 2 centres, in addition, Area 1 were able to offer outreach services. Area 1 centre also agreed that Leigh could arrive without an appointment at any point, and she would be seen. This evidences that they knew that she was not able to keep to her appointments and offered excellent person-centred care. This provides learning from strong practice as a way of keeping people engaged who may struggle to engage and fits in with Trauma Informed Approaches discussed later in this section.

7.14. On her discharge from hospital in the timeframe of the review, Leigh's mental health remained stable. This was largely due to the tenacity of the ASC SW and the CPNs within Mental Health Trust community team who consistently messaged and phoned Leigh and accompanied her to her depot injection appointments. Despite some missed appointments Leigh received enough medication to keep her mental health stable. The review identified that although her depot could have been given at home, that to encourage attendance at appointments and to take responsibility for attendance was part of her mental health recovery and therefore was in Leigh's best interests. It is important to note that sometimes, a recovery model that encourages self-determination may not always fit in with Trauma Informed Approaches and needs to be assessed on a case-by-case basis.

7.15. When the GP practice learned of Leigh's admission, a note was put on the system to ensure that Leigh was sent an appointment to be seen on discharge. Part of the plan was for the GP to discuss ongoing treatment options for Leigh regarding her HIV and to encourage engagement with HIV services.

7.16. Unfortunately, this did not happen. The appointment letter was sent, but the non-engagement was not followed up. This was at a time that two GP practices were merging, and there were different electronic systems in the two practices. This issue has been subject to recommendations made by the CCG in their

single agency learning for this review.

7.17. Leigh's social and mental health needs were to be met on discharge by the ASC social worker acting as care coordinator and the mental health reablement team working to support Leigh with her rent arears and housing solutions.

7.18. Whilst the discharge planning meeting was well attended there were no further multi agency/disciplinary team meetings. Whilst there was some evidence of good communication between services, each continued to work on their own remit and element of Leigh's care. In essence this meant that multiagency working was not effective in identifying emerging health issues.

7.19. Having been subject to detention under Section 3 of the Mental Health Act, Leigh was entitled to s117 aftercare. Although the aftercare that Leigh received was in line with her needs there was no 117-aftercare plan, and the CPA care plan was not reviewed. Both of these care plans should have been incorporated into a joint plan. Whilst the s117 plan is very much about mental health readmission prevention, the CPA care plan is a holistic plan. The CPA care plan should be reviewed every six months and as needs change and was therefore due for review three months prior to Leigh being admitted to the Acute Hospital NHS Trust when she was physically unwell. A CPA care plan should draw information from other agencies and on occasion may result in a multi-disciplinary/agency meeting.

7.20. Given that the first mention of Leigh's physical appearance being cause for concern happened two months before the CPA review was due, that it was known that Leigh still had housing issues (was living with a friend) and was not engaging with HIV services, it is reasonable to have expected that the CPA review might have drawn together a holistic view of how Leigh really was managing her life post discharge.

7.21. Had this review taken place, then it may have been easier to have drawn everyone back together the following month when there were notable issues with Leigh's physical health. A multi-agency review would have also engaged the GP and identified that Leigh had not taken the advice of the mental health doctor at outpatient clinic or the health assessment nurse a couple of weeks later. It was already known that Leigh did not engage with healthcare appointments easily, but on several occasions when her health was declining, there was a reliance on Leigh to access care and support for herself. Having a holistic view of Leigh, it should have been recognised that this was unrealistic for Leigh even with the support of her daughter and friend. Engagement and support to attend needed to come from professionals in the same way that the support to engage with depot injections had been managed.

7.22. Leigh had HIV that was untreated from the time of diagnosis seven years previously. Specialists in HIV disease progression informed the review that it would be reasonable to expect that this would eventually lead to a breakdown in her immune system and lead to physical healthcare complications (See Appendix Two). It does not appear that the urgency of the physical deterioration was understood or acted upon in a timely manner. The conversations between services for HIV whilst Leigh was an inpatient on the mental health ward did not highlight that any of Leigh's psychotic presentation could have been due to HIV disease progression.

7.23. The workshops noted that treatment for HIV and recognition of complications of HIV are not well. understood by mental health staff. There is a general belief that people no longer die from AIDS, as

treatment for HIV is largely successful. Had there have been a greater multi agency approach that included HIV specialists throughout, with appropriate professional challenge and sharing of information, it might well have supported all involved professionals to understand that Leigh's decline was definitely related to her untreated HIV and required urgent assessment and treatment. As a result of Leigh's death, an education session was delivered to mental health staff by the specialist HIV service in Area 2. This session was reported to be well attended. The learning from this review is likely to lead to wider information regarding issues of untreated HIV.

7.24. It is also questioned during the review as to whether there should have been more professional support to ensure that Leigh could find solutions to engaging with HIV treatment earlier in order to prevent the inevitable deterioration. Professionals and Leigh's family all informed the author that Leigh was adamant that she did not want treatment. The reliance on monitoring Leigh's blood for signs of increasing risk from the disease developing to an AIDS defining illness, relied on these tests being undertaken regularly. Leigh did not engage with HIV services during the period under review, so the blood monitoring was not effective and disease progression was not noticed clinically. It could be suggested that if Leigh was not having her blood effectively monitored, that there needed to be contingency planning and sharing of information of what to look out for and what action was required to be taken by those who were not HIV specialists. This again could have come from a multi-agency approach.

7.25. It is of note that Leigh died from developing an AIDS defining illness of a viral brain infection leading to damage to the brain. It is known that this complication is now extremely rare but could have accounted for Leigh's deteriorating behavioural presentation that resulted in the psychosis diagnosis if the infection was related to the part of the brain that controls behaviour. At no point was there a suggestion that her behavioural presentation could be due to her HIV and therefore leads to learning. An MRI scan of the brain during the mental health admission under MHA section 3 could have led to an earlier diagnosis and is therefore learning and a reminder that even rare complications do occur and should be considered by specialists.

7.26. Albeit that the later outward symptoms were of self-neglect, and this is discussed in the safeguarding section, the physical health symptoms, made known to HIV services would have triggered urgent planning to ensure that Leigh was assessed much sooner.

7.27. The care coordinator, being the social worker understood that the role was to focus on social care issues and had assumed that the health side of Leigh's needs were being met elsewhere. The care coordinator role was not fully undertaken in this case in the way that CPA is intended. The local authority has accepted the learning related to this case regarding the CPA care plan, role of the care coordinator and s117 aftercare plans. It is of note that at the time of this case, the local authority mental health team and the NHS mental health team, were an integrated team hosted by the NHS Mental Health Trust. Much of the recording at that time was on the mental health records system and not the local authority one. This caused issues in that there was not a whole record on the local authority system regarding Leigh. Since the social work element of mental health teams has moved back to the local authority this issue is resolved.

7.28. It is also of note that no other professionals challenged that there had been no CPA review. Whilst Acute Hospital services may not understand the role of CPA, other mental health colleagues could have asked for

a review.

7.29. The local authority has no record of the conversation that took place between the social worker and manager when concerns were escalating. It is important that case specific supervision, guidance, advice, outcome and actions are recorded in a case note within the person's record. This enables clarity of communication as well as ability to review agreed actions. This will be subject to a single agency action.

7.30. Leigh was assumed to have mental capacity to make decisions to access her own healthcare appointments; capacity was not formally assessed or recorded, however. Had there been a multi-agency approach, this position may well have been challenged, causing services to formally assess Leigh's capacity to make decisions regarding her physical healthcare.

7.31. There was an apparent confusion regarding who Leigh's current GP was once she had been granted the new tenancy. One of the tasks when Leigh was given her new tenancy was to register with a local GP. The ASC SW attempted to support this and took the registration form to the new practice. The receptionist identified that the registration form needed to be accompanied by two forms of identification to complete the registration process and so handed back the registration form. When ASC SW offered to take these to the practice, Leigh stated that she would do that independently and later told the ASC SW that she had done this. Having believed that Leigh had registered with the new practice, an appointment was made for Leigh to see the appropriate mental health doctor based on her new GP practice. The outcome of that appointment was shared with the new practice, but they had no record of Leigh. Services of psychiatry teams within the Mental Health Trust are based on the locality that the patient lives and is defined by the area of the GP practice. It was therefore necessary to identify who the new GP was to identify who would be the appropriate psychiatry team.

7.32. Given that there was delay in arranging this appointment until Leigh registered with a new GP and that the registration was never completed, the author questioned whether this change of GP practice was necessary as it added confusion into the situation. Leigh had been registered with the same practice from when she had moved to the region. There were several factors to consider. Leigh was known to the original practice; she had only moved to a flat that was three miles from one of the practice sites and in fact spent most of her time at her friends that was only two and a half miles from the practice. It was explained by the GP practice that three miles was indeed well out of their catchment area and creates difficulties as patients living that far away cannot get home visits. Learning regarding this relates to ensuring that vulnerable clients are registered with a GP, with new registrations being actively followed up by professionals to identify if further support is required to complete registrations.

7.33. There were several questions raised in the workshop regarding the possible barriers to Leigh's friend doing more and not doing what she had said she would. There are several things to consider here. The friend had her own difficulties, however, Leigh stated that she felt safe with her friend. Each time professionals spoke to the friend, there was no indication that the friend was not caring and would not do what she had said she would. One of Leigh's daughters was living with her, but she too had her own difficulties and was not able to support Leigh. Professionals did not understand or know of the difficulties that were facing those that were relied on to support Leigh.

7.34. There needed to be greater focus on multi agency working and collaboration by those working with Leigh, with effective challenge and a true understanding of Leigh's mental capacity as her physical health was deteriorating. Increased multi agency working may have led to a realisation of the complexities of the case as time moved on. This may have led to more professionals seeking support and supervision. There is little evidence of formal supervision in the agency reports. Adult Social Care have recognised that the seeking, offering and recording of supervision in this case was not in line with policy and have made single agency recommendation regarding this. Seeking support and supervision from supervisors and managers may have provided an objective and reflective review of the difficulties that professionals were having in maintaining contact and engagement with Leigh. These elements have led to learning for assessment care and review.

7.35. As mentioned above, an element that may have further supported Leigh in the care that was delivered to her was more of a Trauma Informed Approach (TIA). It has been known for many years that trauma impacts on mental health[10] as well as cognitive abilities[11]. The trauma experienced by Leigh started in childhood and continued into adulthood and throughout her life. Events that occurred were evidence of her ongoing trauma and responses to that trauma e.g., her difficulties with neighbours, the ongoing knowledge that her HIV had been deliberately inflicted on her as part of the abuse she was victim of and the trauma of losing care of her children to her abusers are just some examples.

7.36. Many professionals understood some of this trauma but very few knew the whole picture. There was some evidence of TIA, e.g., not insisting on appointments for Leigh to receive HIV support and the work of the CPNs and ASC SW to ensure that Leigh was able to get treatment. These flexible approaches show some understanding of the needs of a person that may have experienced trauma who struggles to engage with services and manage appointments.

7.37. It can be seen, however, that there needed to be a much more obvious acknowledgement of the impact that the trauma was having on Leigh's ability to function and respond to the needs of services. Aspects of TIA are discussed in various articles and include:

- Safety,
- Trustworthiness and Transparency
- Peer Support
- Collaboration and Mutuality
- Empowerment, Voice and Choice
- Cultural, Historical, and Gender Issues

7.38. It is important that services are able to adopt a 'trauma lens', have a shared understanding of, and approach to working with people whose lives are showing the significant impact of trauma.

[10] Mauritz, M., et al. (2013), "Prevalence of interpersonal trauma exposure and trauma-related disorders in severe mental illness", European Journal of Psychotraumatology, Vol. 4, available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC3621904/

[11] Majer et al. Association of childhood trauma with cognitive function in healthy adults: a pilot study BMC Neurology 2010, 10:61 http://www.biomedcentral.com/1471-2377/10/61

7.39. It is not possible to know at this point how much Leigh's behaviour was as a direct impact of trauma and how much was as a result of her developing AIDS from untreated HIV; there is learning for assessment care and review in managing both of these features.

**Improvement Points:**

- GPs are an active source of up to date information on who is working with a person
- Frameworks for assessment, care and review are an effective tool for multiagency working
- Professional challenge, escalation, supervision and support all enhance reflective practice and can lead to positive outcomes.
- Where a health condition is not being treated and is likely to lead to deterioration and possible death, active engagement for solutions and contingency planning that includes what might indicate decline are important tools for all working with the person.
- Rare complications of diseases do occur and should be actively considered until they are ruled out.
- Trauma informed approaches used on a collaborative basis provide evidence-based care to those whose lives have been impacted by trauma.
- Professionals who are supporting people with access to new GPs when they move address, need to ensure that the new GP practice has received the application and that vulnerable people have active GP cover locally.

### Discharge Planning and Housing

7.40. Both of the mental health admissions discussed within this report evidence that much of the planning for discharges revolved around Leigh's housing need. Leigh's house fell into a state of disrepair largely due to Leigh's inability to engage with services and ensure that she paid her bills and allowing housing repair services access to carry out repairs.

7.41. It is important to note that Leigh had a fear of letting male service workers into her home. Leigh was supported to be away from her property for repairs to be carried out which was good practice, but Leigh often returned. The section above explains why Leigh may have been presenting in ways that were not in her best interests but that she may have had no control over. It is important to remember that Leigh had a history of being quite a different person albeit suffering from impacts of trauma. The learning here is related to closer multiagency working in order that all issues are considered and understood by all agencies and is discussed later in this section.

7.42. There had been significant difficulties previously within the neighbourhood for Leigh. Her presentation and psychotic behaviours impacted on the contacts she had with neighbours; this was exacerbated when the local community became aware of Leigh's HIV status. Leigh was very unhappy and did not feel safe in that address.

7.43. On discharge just prior to the timeframe for this review, attempts were underway to ensure that these housing repairs were undertaken. As seen in section five, this did not happen, and Leigh returned to conditions that were not suitable. Leigh's mental health had not received any effective treatment at this stage, and she did not agree to wait until some of the most serious housing issues were resolved prior to

discharge.

7.44. On the second admission, the housing issues were similar with the discharge planning addressing housing concerns as soon as Leigh was clinically fit enough to be engaged in conversations related to her housing need.

7.45. The difference on this admission was twofold. Leigh's mental health became more stable, and she had also been detained on a Section 3 of the Mental Health Act which meant that she was eligible for S117 aftercare. One of the key features of S117 is to ensure that housing and support needs are met in order to prevent readmission. This meant that Leigh was supported by a mental health social worker and the mental health reablement team who started to work with Leigh prior to discharge. The mental health inpatient team also worked hard to ensure that Leigh's housing needs were met and engaged the occupational therapist.

7.46. This all led to conversations with housing services to identify what exactly was needed in terms of repairs and future housing solutions. This was strong practice in working with Leigh as soon as she was able to identify what she wanted in terms of housing.

7.47. The review heard that there are two elements to the housing service. One is the Homefinder service who support tenants with applications for housing and finding suitable accommodation, the other is the local authority housing department neighbourhood teams who manage existing tenancies, rents and maintain housing stock.

7.48. It appears that the Homefinder service held a large amount of information related to the needs of Leigh. Albeit that the Homefinder service did not attend any discharge planning meetings, they did understand some of Leigh's need. Leigh, as a current tenant with arrears and tenancy issues around the condition of her property, would fail to be eligible for a transfer through the usual Homefinder route. Concerns around mental health, safeguarding and financial difficulties needed to be considered to enable this to go ahead. Close working between Homefinder and neighbourhood housing teams would facilitate this. However, it appears that some key information relating to Leigh's housing related needs were not identified or shared, therefore a transfer was identified on the basis of providing smaller, more efficient, and lower rent property with no repair issues, as the property was new.

7.49. The local authority neighbourhood housing team told the workshops that they were surprised how little involvement that they had in communication and forward planning for Leigh. Conversations between other agencies and housing did take place but were informal. There is therefore learning for how the two elements of housing services communicate with each other and other agencies when working with vulnerable people who have complex needs. As a result of this learning, Housing are now engaged through a contact point in hospital discharge meetings and the point of contact is of appropriate seniority to enable actions and learning to be disseminated through all housing teams.

7.50. Leigh was an inpatient for a total of nine and a half weeks; it took six weeks to stabilise her mental health. It was not possible to gain permission from Leigh to undertake repairs and gain access to the property until this time. Once Leigh's mental health stabilised, she improved very quickly. As Leigh was then quickly fit for discharge, there was then a sense of urgency not only to identify a new property for her to move to but to

resolve rent arears and ensure that the repairs were carried out. As housing were not party, in the main, to Leigh's needs, consideration was not given to supported housing or the exact nature or location of the housing requirement.

7.51. When the decision was made that it would be beneficial for Leigh to move to Area 2, and Leigh had agreed, Homefinder services indicated that as Leigh had no local connection to that area, it was not an option and other options in area 1 were explored. Housing colleagues at the workshops indicated that being closer to essential health services was actually considered a local connection and would have been grounds for an application for housing in Area 2. Mental health NHS and social work staff were not aware of this and there was no challenge to the decision that Leigh could not be housed in Area 2.

7.52. It was discussed that it was going to take more time than anticipated to find suitable housing, therefore Leigh agreed to be discharged to her existing home on the understanding that other options would continue to be pursued. It was not possible for Leigh to remain an inpatient on a mental health ward until housing needs were addressed. The occupational therapist visited Leigh's address with her and supported her to make it ready for her discharge by cleaning and tidying it.

7.53. Ultimately, when Leigh was discharged, she did not spend any time at her address and almost immediately went to stay with her friend. When Leigh was offered the flat in Area 1, she viewed it and signed for the tenancy but only ever spent a couple of nights there and on those occasions, her daughter stayed with her. Leigh appeared to choose to stay with her friend and daughter in an environment that was reported by Leigh's other daughter and professionals who gained access, as dirty and cluttered, where there was no bed for her, sleeping on a mattress on the floor that she shared with her daughter, rather than stay in her new build flat.

7.54. When Leigh's sister spoke with the author, it was identified that Leigh had a great fear of being alone. Some professionals did know this as it was evidenced in single agency reports. A discussion within the workshop identified that although Leigh stated that she did not like being on her own, she knew that she needed space from her daughters and time to reflect and sort her life out. In reality, Leigh was not able to do this. One comment at the workshop that describes this dilemma was that it was Leigh's best/worst option i.e., in consideration of the impact of trauma leading to a fear of being on her own, the unsuitable and unhygienic circumstances were the best option for her not to be alone. Leigh was used to having her five children with her; her younger children were now living away from her and her older daughters had difficult relationships with Leigh.

7.55. It can be seen that there were a lot of professionals trying to do their best to ensure that Leigh had access to safe, affordable housing that was close to her daughters and friends with room for her daughters and children to stay occasionally. This was in fact achieved. It is clear, however, that this did not encourage Leigh to stay in her new property; the review understands from the circumstances that the new property did not truly fit with solutions that Leigh could live with.

7.56. In order to consider the learning in relation to housing and discharge planning, there are links to the previous section.

7.57. Discharge planning and housing issues needed to have a more collaborative multi agency approach. Use of the CPA and S117 planning could have identified the issues facing Leigh and drawn in housing staff. This would have enabled housing staff to have a greater understanding of the issues facing Leigh and her needs. Housing staff indicated that they have not generally been invited to multi-disciplinary team meetings. Mental health inpatient staff stated that they had not considered inviting housing staff to meetings. This appears to be a gap in multi-agency working. It is not an unusual situation for those people in hospital to have housing needs.

7.58. All agreed that there was an opportunity to consider this moving forward as a way to ensure robust communication between health and social care and housing as well as other services/agencies regarding a person's housing needs. The discharge facilitator for the ward that Leigh was an inpatient on has started a housing forum due to issues of understanding the different housing service structures and associated services across the region. Housing staff involved in this review were not aware of the forum; information related to the forum will be shared.

7.59. Housing staff have stated that they need to have a more joined up approach between the housing allocation function and the neighbourhood teams.

7.60. Albeit in this case, Leigh was not initially able to consent to repairs as she was too mentally unwell at the time, tentative discharge planning could have started earlier to identify what the specific issues were. This would have meant that as soon as Leigh was well enough, housing plans could be commenced promptly. It was not anticipated that Leigh would suddenly improve once medication started; however, this should not have stopped tentative planning.

7.61. It is important to note that professionals made an assumption of capacity when Leigh was mentally well and dealing with discharge planning and housing decisions within the time frame of the review (notwithstanding that Mental Capacity had been assessed regarding the discharge that was prior to the timeframe). Single agencies have recognised this as learning and made appropriate recommendations.

7.62. The other element of understanding Leigh's housing needs was to understand what Leigh really needed in terms of her experience of trauma. It does not appear that TIA were considered in terms of her housing need. Because of this there was no exploration as to whether short term solutions to offer more in-depth support on discharge could have helped Leigh take the time that she stated she needed to reflect and get her life back on track. This appears to be an unmet need. The support Leigh had on discharge was good but was very service specific e.g., to ensure that she had accommodation, that her bills and rent arrears were resolved, that she attended for her depot injections and that she attended for her HIV appointments. Once the apparent remit had been met, the mental health reablement service discharged Leigh. With no s117 active care plan, the outcome from the work of the service was not evaluated and no further actions to support Leigh were identified.

7.63. If trauma and lifestyle of Leigh had been understood as possibly having a significant impact on Leigh being able to live independently on discharge, supported housing might have been explored with Leigh as an option to support her needs more comprehensively and holistically. As stated previously Leigh was assumed to have capacity to make decisions; it was not considered that Leigh would have any struggles to

live independently.

7.64. It was agreed during workshop discussions that one of the issues was that there was no suitable step-down provision between acute mental health inpatient beds and discharge to community, especially where there are unmet housing needs. In the case of physical health care, such beds exist providing a place of safety and support for people with whilst alternative accommodation and care packages are sought. This prevents acute hospital beds from being used by vulnerable people who no longer have the need for acute hospital healthcare but are not ready for discharge for whatever reason. No such provision exists for vulnerable mental health patients. Those in the situation that Leigh was in would benefit if this gap was explored in more detail and solutions found. It is a known fact that there is a national shortage of mental health inpatient beds; situations like the one that Leigh was in, can lead to delays in discharge or discharges under pressure.

**Improvement Points:**

- Robust CPA and s117 care plans provide a vehicle for planning for discharge including housing need, with all post discharge work included and evaluated**.**
- Early tentative discharge planning alongside Involvement of Housing Colleagues in MDT meetings may improve discharge planning options.
- Housing solutions fully explored based on identified need can benefit those in need of extra support.
- It is important that separate departments of the same service are able to work effectively together and share information (i.e., in this case housing).
- Trauma informed approaches are relevant in understanding a person's housing need.
- There would be a benefit from exploration of stepdown provisions for mental health patients where housing and other social issues need resolution before a safe discharge.

### Safeguarding and Self Neglect

7.65. The workshop discussed the safeguarding alert that was just prior to the timeframe for the review. It was strong practice to recognise that the issues that Leigh was facing were a safeguarding risk. The alert from the Area 2 hospital health psychologist was not evidenced in the local authority information for this review. There is no audit trail of the process and outcome of this referral. This has been explained by the local authority as being a system issue in relation to how mental health safeguarding referrals were previously managed. As the mental health team for social care and health were integrated at the time, the referral was sent from the Adult Social Care Gateway team to the CPN for follow up. There is a record of some of the discussions between the CPN and the referrer; not all of the issues in the referral were discussed but it appears Leigh agreeing to attend the housing office to address her housing needs was the only outcome that can be identified.

7.66. This showed some inadequacies in the system at the time and there is no evidence that it was investigated as a safeguarding concern with any clear decision making as to whether the referral met the safeguarding threshold or whether signposting elsewhere was needed. This was a missed opportunity to address the housing issues and all of the other issues that had been raised as a concern in the referral. If the response to the safeguarding referral had been more robust, a social worker could have been allocated to undertake a care and support assessment to assess and address Leigh's needs much earlier in the timeframe for this

review as an adult at risk even if the threshold for section 42 enquiry was not met.

7.67. The local authority has since changed the way that safeguarding concerns are processed. Ongoing audits provide assurance related to this.

7.68. There were many aspects of Leigh's life during the timeframe for this review that indicated self-neglect. Self-neglect is defined in the Care and Support Statutory Guidance[12] as:

> 'a wide range of behaviour including neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding'.
>
> - Lack of self-care (e.g. neglecting personal care, hygiene and health; poor diet and nutrition) and/or,
> - Lack of care of their domestic environment (e.g. neglecting home environment, hoarding and excessive clutter) and/or,
> - Refusal of services that could mitigate the risk to safety and well-being (e.g. lack of engagement with health and/or social care staff and other services/agencies)

7.69. This identifies that Leigh fitted the criteria of self-neglect; she was at risk of harm because of her lack of self-care for her physical health needs as well as possibly due to the impact of trauma.

The Guidance mentioned above also states that:

> 'It should be noted that self-neglect may not prompt a section 42 enquiry[13]. An assessment should be made on a case by case basis. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support'

7.70. No further safeguarding referrals were made until Leigh's final admission when referrals were made related self-neglect due to the circumstances that Leigh had been found in. It was acknowledged that Leigh was safe in hospital and no longer self-neglecting but that plans would need to consider further prevention on discharge.

7.71. When the further safeguarding alert was raised by family these progressed well and were appropriately recorded, followed process; sadly, Leigh died before investigations could be concluded.

7.72. It is recognised in research[14] and Safeguarding Adult Reviews[15] that working with cases of self-neglect can be particularly complex. The research [(ibid)] recognises that there is a need for practitioners to understand

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[12] **Care Act Guidance: Care and Support Statutory Guidance** (2016) https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance
Updated 2018 with no changes to Chapter 14 Safeguarding

[13] **The Care Act 2014 (Section 42)** requires that each local authority must make enquiries, or cause others to do so, if it believes an adult is experiencing, or is at risk of, abuse or neglect. An enquiry should establish whether any action needs to be taken to prevent or stop abuse or neglect, and if so, by whom.

[14] Braye, S. Orr, D. & Preston-Shoot, M. (2015) **Self-neglect policy and practice: key research messages.** Social Care Institute for Excellence available at https://www.scie.org.uk/publications/reports/report46.pdf

[15] Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews', *Journal of Adult Protection*, 17, 1, 3-18

self-neglect and to develop skills in effective interventions. There are four key elements to best practice approaches to working with people who self-neglect:

- Importance of relationships
- Understanding the person
- Legal literacy
- Creative interventions
- Effective multi agency working

7.73. Key in managing self-neglect in the case of Leigh was the need to build a trusting relationship, understanding why she was self-neglecting as well as effective multi agency working. Again, it cannot be stressed enough that it was likely that Leigh's deteriorating physical health, now known to be from untreated HIV, as well as some impact of the trauma within her life was affecting her self-esteem and lifestyle. It was noted by professionals that Leigh was often dishevelled, what was not recognised or addressed was when this tipped over into something more significant that led to her life becoming at risk.

7.74. Leigh was recognised as at risk of self-neglect on admission at the beginning of the timeframe for the review. This was good practice to recognise this as a risk, it did not, however, lead to any planning related to how this should be managed either on the ward or on discharge.

7.75. Following discharge, it was four months later that it was first noted that Leigh appeared to be not caring for herself. Several professionals noted this worsening state and three months later considerable concerns were noted in the mental health outpatient clinic. Whilst there were attempts to understand what was physically wrong with Leigh, there was no recognition that there was associated self-neglect and so it did not trigger any referrals.

7.76. It was recognised at the workshop that there is a good guidance related to self-neglect in the local area[16]. The added element that Leigh was appearing not taking advice related to seeing her GP or attending hospitals to find out the cause of her physical health symptoms was not recognised as part of the self-neglect that became evident because her progressing HIV as discussed extensively previously in this report.

7.77. It is not clear what the barriers were to agencies recognising the benefit that a safeguarding response may have brought or to enable them to articulate that Leigh was displaying significant symptoms of self-neglect. A hypothesis was put forward at the workshop that it may be that staff were used to seeing a certain amount of lack of self-care in clients and service users and may have differing thresholds than maybe the general public would have. For this reason, it is important to promote the use of the guidance that has very clear explanations of when a safeguarding response may be required.

7.78. The benefits of a safeguarding referral would have been bringing together safeguarding leads and provided a different lens other than focusing on mental health and physical health. In exploring self-neglect as a safeguarding issue, one of the major factors would have to have fully assessed Leigh's capacity to

[16] **Self-Neglect Guidance** North of Tyne (North Tyneside and Northumberland) February 2016
https://my.northtyneside.gov.uk/sites/default/files/web-page-related-files/Self%20Neglect%20Guidance.pdf

understand and decide to self-care or not. It also needed to be assessed whether Leigh understood, that without addressing her health care needs, that her physical health would be further impacted and place her at serious risk of harm. The records do not show that Leigh was challenged regarding her apparent choice to neglect herself. Without this challenge and robust mental capacity assessment it was not known if this was indeed a capacitous decision or whether something was affecting her capacity and motivation to self-care i.e., the now understood AIDs defining illness.

7.79. It is important to stress that Leigh having an AIDS defining illness was not known at the time and therefore care needs to be taken not to apply hindsight bias. The Social Care Institute for Excellence (SCIE) warns against use of hindsight bias stating that it is an obstacle to learning[17]. In this case, however, had a multi-agency approach and professional curiosity been applied in understanding Leigh's decline and self-neglect, then this information could have been knowable i.e., by supporting Leigh more effectively to undergo further testing for her presenting symptoms, rather than the reliance on her to attend her healthcare appointments. Mental capacity assessment needed to be undertaken earlier in the timeline when concerns were first being raised; Leigh declined contact and access later on.

7.80. It is now known that it was Leigh's physical health condition that was making her very unwell and was likely to be affecting her mental capacity. If professionals had the confidence and knowledge to address the self-neglect as an obvious outward symptom, it would have drawn in questions regarding who was supporting and advocating for her and how her CPA and s117 care plans were safeguarding her. A safeguarding plan earlier may also have led to prompt escalation when professionals were having difficulty seeing Leigh in the weeks leading up to her admission to hospital.

7.81. Even if the threshold for S42 was not met, there were other routes that a referral could have led to e.g. that the CPA/S117 care plan review with a multi-agency focus.

7.82. The purpose of Safeguarding procedures and guidance are to ensure that there is a level playing field when it comes to who requires safeguarding and not left to individual professional judgement based on their own experience and usual client group.

7.83. This led to a conversation within the workshop regarding the accessibility to professionals of procedures and guidance. It was identified by the author that there is no specific website for the Joint Safeguarding Adults Board; all safeguarding adults' material and advice is located on the Local Authority websites. Professionals stated that they did not have a problem accessing multi agency procedures. Some agencies identified that they do have copies of the multi-agency procedures on their internal (intranet) sites, and all have their own procedures. It can be difficult to keep individual documents updated; a more useful approach would be to have links to a dedicated safeguarding adult board website that agencies can have links to on their own intranet sites. It is noted that there is a portal for professionals to use to make safeguarding referrals and this is encouraged as a preferred method of referral. Emails regarding concerns can also be sent to the Adult Social Care Front Door.

[17] **SCIE:** Safeguarding Adults Reviews (SARs) under the Care Act https://www.scie.org.uk/safeguarding/adults/reviews/care-act#:~:text=Hindsight%20bias%20poses%20a%20great%20obstacle%20to%20learning%20through%20SARs.&text=Knowledge%20of%20the%20outcome%20biases,were%20involved%20at%20the%20time.

7.84. The author has reviewed the safeguarding procedures and identified that an update that includes flow charts to illustrate each part of the process that are often helpful to busy professionals, may be beneficial. The current '10 steps to safeguarding' leaflet is in the process of being reviewed and does have a flow chart within it. The author suggests that each step could have a flow chart rather than one flow chart for the whole process.

7.85. It is also of note that Safeguarding Adult Boards are multi agency, having a collective responsibility for safeguarding adults in their area; information held on a local authority website does not give the impression of being a collective responsibility. The author's experience is that most SABs have their own website. All those present within the workshops felt that a dedicated website would be beneficial. The joint SAB arrangements are subject to a current peer review. Whatever the outcome of this, a new or same model for Board arrangements would benefit from dedicated websites in order to promote the multiagency nature of SABs.

7.86. There were some elements of good communication in the work undertaken with Leigh that have been identified earlier in this report. When considering the safeguarding elements that were presented, there was not very much communication and collaborative working between those working with Leigh and those working with her daughters. There is evidence throughout the chronology, that there was ongoing tension and difficulties in the relationships between Leigh and her daughters. All had their own workers in the local authority.

7.87. It was acknowledged within the workshops that there could have been more communication between Leigh's and her children's services throughout the timeframe of the review. There may have been benefits to Leigh and her daughters in using a 'Think Family' approach. Think family approaches are more associated with younger children and their families but there is no reason why this framework could not form part of working with care leavers and parents where there is still a relationship, particularly where all have issues and trauma that they are working through.

7.88. The Think Family framework[18] was originally identified as a useful toolkit when working in cases where parental mental health was an issue. It has been recognised that this framework is useful when it is identified that any issues affecting parents result in services working with adults (e.g. physical health, learning disabilities etc.). This framework recognises that no parent or child exists in isolation and that when an issue affects an adult it has an impact on the child and vice versa. Leigh and her daughters may have benefitted from stronger communication between their key workers. This may also have led to questions regarding Leigh's lack of contact with the younger children that upset her so much.

[18] SCIE 2014 Think child, think parent, think family: a guide to parental mental health and child welfare http://www.scie.org.uk/publications/guides/guide30/files/guide30.pdf

**Improvement Points:**

- Guidance and procedures that are easily accessed and visible promotes their use.
- Application of professional curiosity provides an ability to question assumptions.
- Safeguarding responses can offer an alternative lens on a complex situation, can highlight gaps that have not been considered and draw in professionals with specific expertise.
- Think family approaches can benefit family working and relationships.
- Practice and legislative frameworks e.g. Mental Capacity Act offer safeguards to people particularly when they have multi agency involvement.

## 8. CONCLUSION

8.1. Leigh continued to suffer from the trauma that she experienced throughout her life. Her ability to self-manage her life and achieve goals was probably severely disrupted by this. Leigh had a network of professionals around her offering services covering all elements of her needs. Many of the professionals involved had worked with Leigh for a considerable length of time and many knew her very well. This is to be applauded and celebrated as it is not often the case. It appears that all of those working with Leigh were keen support her but did not appear to be able to effect change.

8.2. It was the difficulties in managing her life that led Leigh to believe that she would not be able to comply with HIV medication regimes and therefore left her at risk of developing an AIDS defining illness. None of Leigh's physical health or behaviour presentations alerted any of the professionals that Leigh was now into the final stage of HIV disease progression and as such required immediate medical assessment and treatment.

8.3. In order to support Leigh in her mental health recovery Leigh was encouraged to have a self-directed life where she was encouraged to access housing services, medical appointments and to manage her day-to-day life. It appears that her mental health recovery was focussed on the medical model of ensuring that she had her depot medication on a regular basis. This was largely achieved by the work and tenacity of those working with her.

8.4. The mental health reablement service worked with Leigh to ensure that her housing needs and rent arears were met. Once this had been achieved, the service ended. The outcome of this work was not included in s117 plans and therefore was not reviewed to identify any outstanding needs.

8.5. The recovery approach did not appear to be a strengths-based approach that accounted for Leigh's reaction to the trauma that she had been through. There was no documentation that evidences an in-depth understanding using trauma informed approaches. There is very little recorded regarding Leighs goals and how she was going to achieve them moving forward. Leigh did know what she wanted but it appeared that she did not know how she was going to achieve it.

8.6. There were missed opportunities to ensure a full multi agency care plan, collaboration and communication that may have afforded Leigh enhanced support and safety. Without this there was no recognition there were physical health symptoms that were leading to significant self-neglect. Professionals did not access the guidance that was available to them as they did not recognise that Leigh was self-neglecting. A

safeguarding approach could have been the framework for multi-agency working. Although professionals did focus on the medical issues that Leigh presented with, they relied on her to be able to access the medical services that could further investigate the causes of her symptoms when she was significantly unwell and would find this very difficult. Professionals did not recognise that Leighs symptoms were indicators of her HIV disease progression.

8.7. Strong practice has been identified throughout this review with learning identified in each section and leads to recommendations for improvement and support for stronger practice.

## 9. RECOMMENDATIONS

9.1. The findings identified above have been included in learning points throughout this report and lead to recommendations for improvement.

9.2. Where agencies have made their own recommendations N&NTSAB should seek assurance that action plans are underway, and outcomes are impact assessed within those organisations.

9.3. The following multi agency recommendations are made to the N&NTSAB as a result of the learning in this case:

### SAB Assurance Role

1. The SAB should seek assurance from relevant agencies that internal audits identify:
    - robust use of frameworks e.g. CPA, Safeguarding, s117 planning
    - there is appropriate supervision in place

    and that improvement action is taken where required.

2. The SAB should seek assurance that all relevant agencies who gather information to inform their assessment/practice have prompts in assessment proformas for seeking out Adverse Childhood Experiences and other traumas that are current and/or historic. Relevant agencies would be those who undertake scheduled assessments rather than those who are assessing in unscheduled and emergency situations.

3. The SAB should require agencies to raise awareness within front line teams of the awareness and implications of the long-term effects of untreated HIV disease. This should include where to seek specialist advice and support when working with a person who is HIV positive who is not receiving treatment.

4. The SAB should ask Housing and The Mental Health NHS Trust to identify how housing departments across all the Local Authority Areas that The Mental Health NHS Trust cover, can be included in MDT meetings where appropriate. This should result in guidance for staff in both housing and The Mental Health NHS Trust.

5. The SAB should seek assurance that all agencies have access to the SAB Self Neglect Guidance and that it is accessed and embedded in practice. In particular the importance of understanding that Mental Capacity is at the forefront (as per the guidance). This may require a review and relaunch.

## SAB Actions

6. The outdated Professional Resolution Policy (from 2012) should be removed from the North Tyneside web page. The production of a SAB 'Professional Challenge and Escalation' guidance/policy should be prioritised. Ways of promoting the new guidance should be considered for greatest impact e.g., via a seven-minute briefing.

7. The SAB should undertake to produce a 'Professional Curiosity' Briefing, supporting the concept to encourage resistance of assumptions in practice.

8. The SAB should identify ways of developing an approach on the lifelong impact of Adverse Childhood Experiences and other traumas. This should include the use of trauma informed approaches when Adverse Childhood Experiences and other trauma have been identified.

9. The SAB should refresh and make use of flow charts in Multi Agency Safeguarding Procedures to ensure inclusion of:
    - Illustrations and flow charts of the process.
    - advice on ways forward for multi-agency working for those that do not meet S42 threshold i.e. lower level multi agency responses such as a team around the person approach as well as other frameworks e.g. CPA, s117.
    - a reminder to 'Think Family' when undertaking adult safeguarding work

10. The SAB should produce a seven-minute briefing, or similar, as a reminder and a refresh of Think Family approaches. The Board and SAB partners should ensure that Think Family, forms part of initial and refresher, single and multi- agency safeguarding training, with consideration for delivery across children and adult workers together.

11. The briefing from this SAR should include the following pertinent points for learning:
    - The importance of active GP cover for vulnerable people especially when they move to a new area.
    - A reminder to all professionals that the GP is a central point for information.

**Safeguarding Adults Review**
**SUBJECT LEIGH**
**Terms of Reference and Scope**

## 1. Introduction

A SAB must undertake reviews of serious cases in specified circumstances. Section 44 of the Care Act 2014 sets out the criteria for a Safeguarding Adults Review (SAR):

An SAB must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if—

(a) there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult, and

(b) condition 1 or 2 is met.

**Condition 1 is met if—**

(a) the adult has died, and

(b) the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

**Condition 2 is met if—**

(a) the adult is still alive, and

(b) the SAB knows or suspects that the adult has experienced serious abuse or neglect.

An SAB may arrange for there to be a review of any other case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs).

Each member of the SAB must co-operate in and contribute to the carrying out of a review under this section with a view to—

(a) identifying the lessons to be learnt from the adult's case, and

(b) applying those lessons to future cases.

The Care Act Statutory Guidance 2014 states that in the context of SAR's "something can be considered serious abuse or neglect where, for example the individual would have been likely to have died but for an intervention or has suffered permanent harm or has reduced capacity or quality of life (whether because of physical or psychological effects) as a result of the abuse or neglect".

All Safeguarding Adults Reviews will reflect the 6 safeguarding principles as set out in the Care Act and N & NTSAB multi-agency procedures. In addition, SARs will:

- Take place within a culture of continuous learning and improvement across the organisations that work together to safeguard and promote the wellbeing and empowerment of adults, identifying opportunities to draw on what works and promote good practice;
- Be proportionate according to the scale and level of complexity of the issues being examined;

- Be led by individuals who are independent of the case under review and of the organisations whose actions are being reviewed;
- Ensure professionals are involved fully in reviews and invited to contribute their perspectives without fear of being blamed for actions they took in good faith;
- Ensure families are invited to contribute to reviews. They should understand how they are going to be involved and their expectations should be managed appropriately and sensitively.
- Focus on learning and not blame, recognising the complexity of circumstances professionals were working within;
- Develop an understanding who did what and the underlying reasons that led individuals and organisations to act as they did;
- Seek to understand practice from the viewpoint of the individuals and organisations involved at the time and identify why things happened;
- Be inclusive of all organisations involved with the adult and their family and ensure information is gathered from frontline practitioners involved in the case;
- Include individual organisational information from Internal Management Reviews / Reports / Chronologies and contribution to panels;
- Make use of relevant research and case evidence to inform the findings of the review;
- Identify what actions are required to develop practice;
- Include the publication of a SAR Report (or executive summary);
- Lead to sustained improvements in practice and have a positive impact on the outcomes for adults.

## 2. Case Summary

Leigh had a long history of psychosis, substance misuse and was HIV positive, with complications. Leigh did not engage with treatment, care and support and was admitted to hospital due to the effects of severe self-neglect, including dehydration and emaciation.

Leigh was eligible for s.117 aftercare following discharge from detention under s.3 of the Mental health Act.

Leigh died in hospital six weeks after admission. The cause of Leigh's death was recorded as being directly related to HIV.

Allegations of exploitation against her friend where she was staying before hospital admission and against her daughter were investigated but no crime was found to have been committed.

## 3. Decision to hold a Safeguarding Adults Review

The Safeguarding Adults Review Committee of the Safeguarding Adults Board met to consider the case for review. Following the collation of chronologies, the case was further considered. It was

agreed by all members present that a formal Safeguarding Adults Review should be undertaken and made a recommendation to the N& NTSAB Independent Chair. The Independent Chair endorsed this decision.

Due to the national response to the Covid-19 pandemic, it was not possible to progress the review until July 2020 when it was agreed that the methodology would be adjusted. (see below).

## 4. Scope

The review will cover the period from date of admission to hospital following a s136 MHA until the date of death. Information will also be sought from agencies regarding background information and key events prior to the scoping period.

## 5. Methodology

The Care Act 2014 Statutory Guidance states that the process for undertaking SARs should be determined locally according to the specific circumstances of individual cases. No one model will be applicable for all cases. The focus must be on what needs to happen to achieve understanding, remedial action and, very often, answers for families and friends of adults who have died or been seriously abused or neglected.

N&NTSAB chose to use a methodology that engages frontline practitioners and their line managers. Agencies are asked to review their own involvement and provide a report of their findings and learning. Those who were involved, alongside the authors of the reviews will then be invited to engage in a series of workshops undertaken using virtual meeting technology. Each workshop will focus on one or two themes and be set the task of exploring the themes and answering questions. The themes will be identified from the chronologies and reports that have been undertaken by agencies. This will lead to identification of areas for learning and improvement

## 6. Key Lines of Enquiry to be addressed

As well as broader analysis provided within the Agency Review Reports, the following case specific key lines of enquiry will be addressed.

### 6.1. Assessment, Care and Review

6.1.1. What assessment did your agency undertake of Leigh's holistic needs, inclusive of physical and mental health?

6.1.2. How robust was this?

6.1.3. How did this inform care planning and interventions?

6.1.4. Please provide analysis of what assessment policies and frameworks were in use and identify any gaps in policy and/or practice. Where appropriate to your organisation please include how CPA and s117 aftercare were involved in supporting assessment, care and review.

6.1.5. Please comment on your agency's response to assessing and managing Leigh's substance misuse, HIV status and mental health.

### 6.2. Mental Capacity Act

6.2.1. Was the Mental Capacity Act applied robustly at points where it should have been?

6.2.2. Please evidence how the mental Capacity Act was applied at various decision points.

6.2.3. What part did Mental Capacity play in understanding the how Leigh managed her life?

### 6.3. Housing Need

How did your agency support and address the ongoing housing need and issues experienced by Leigh?

### 6.4. Engagement

How well did Leigh engage with your service? Please analyse any strategies used to encourage Leigh to engage.

### 6.5. Self-Neglect

6.5.1. What was your agency's response to Leighs apparent self-neglect?

6.5.2. When was it recognised that Leigh was self-neglecting?

6.5.3. What part did safeguarding procedures play in protecting Leigh from self-neglect?

### 6.6. Financial Abuse and Exploitation

6.6.1. What was your agency's involvement in the safeguarding investigation in August 2019?

6.6.2. What were the outcomes of this investigation from your agency's perspectives ?

### 6.7. Family Involvement

How did your agency engage with Leigh's family? What did you understand of the relationship between Leigh and family? How were they included in plans and assessments?

### 6.8. Documentation

Please identify if documentation was in line with agency requirements. If not, please analyse why this might be.

### 6.9. Good Practice

Please identify examples of good practice from your agency and others

## 7. Independent Reviewer

The named independent reviewer commissioned for this SAR is **Karen Rees.**

## 8. Organisations to be involved with the review:

The following organisations will be asked for Agency Review Reports:

- Mental Health NHS Foundation Trust
- Local Council
    - Mental health social work
    - Gateway Team/Safeguarding Team
    - Housing
- Area 1 NHS Foundation Trust
- Area 2 NHS Foundation Trust
- Police
- Ambulance Service NHS Foundation Trust
- Drug Services
- Clinical Commissioning Group for GP

The following organisations/services will be asked for background information to support the review:

- Leaving Care Service
- Local HIV support service

## 9. Family Involvement

A key part of undertaking a SAR is to gather the views of the family, involve them in the review and share findings with them prior to publication. N&NTSAB has made contact with Leigh's sisters, inviting them to be involved. Other family members will also be contacted.

**Project Plan dates:**

| | | |
|---|---|---|
| 1. | Scoping Meeting | 09/07/2020 |
| 2. | Terms of Reference agreed | 09/07/2020 |
| 3. | Agency Authors' briefing | 15/07/2020 |
| 4. | Agency Review Reports submitted | 07/09/2020 |
| 5. | Review of reports by Independent Author | 07-10/09/2020 |
| 6. | Author prepares for workshops | |
| 7. | Distribution of reports & workshop details to all workshop attendees | 02/10/2020 |
| 8. | Learning and Reflection Workshops x4 | W/C 12/10/2020 |
| 9. | First Draft Overview report to all attendees and panel | 06/11/2020 |
| 10. | Comments on First Draft | 20/11/2020 |
| 11. | V2 Overview report circulated to panel | December 2021 |
| 12. | Panel meeting | |
| 13. | V3 to Panel | January 2021 |
| 14. | V4 to Board Members | March 2021 |

**Appendix Two**

**HIV disease progression, monitoring and treatment.**

It's now recommended that everyone diagnosed with HIV starts treatment straight away after being diagnosed. In the UK, national guidelines set out standards for HIV treatment. They currently recommend that anyone with HIV who is ready to commit to treatment should start it regardless of their CD4 count (a measure of the health of your system). https://www.tht.org.uk/hiv-and-sexual-health/living-well-hiv/hiv-treatment/how-hiv-treatment-works

### Primary or acute infection

This stage starts shortly after being exposed to HIV and lasts for a few weeks. There would usually a large amount of HIV in the blood with the immune system responding by producing antibodies.

### Asymptomatic infection

This stage can last for several years, although this can differ greatly from person to person. During this time there would be very few or no major symptoms of HIV infection

### Symptomatic infection

Towards the end of the asymptomatic stage, HIV begins to become more active in the blood. Eventually the body cannot produce new CD4 (to fight HIV) cells quickly enough to keep up with the rate that HIV is destroying them. During this stage the HIV viral load starts to increase and at the same time as the CD4 count falls. As the CD4 count falls further, it is vital that treatment is now started if not already underway.

### Advanced HIV disease (AIDS)

If no treatment is started, HIV would continue to replicate faster and faster, the CD4 count would continue to fall. Symptoms of opportunistic infections or tumours that may have begun in the symptomatic infection stage get more and more severe. This is because the immune system would now be severely damaged, and it would have lost its ability to fight these infections. This leads to a diagnosis with AIDS, and without first treating the infections and then starting anti-HIV treatment, these infections would eventually be fatal. For this reason, the specific opportunistic infections or tumours that result in an AIDS diagnosis are known as **AIDS defining illnesses**

15/12/2020 The stages of HIV infection | GMFA https://www.gmfa.org.uk/the-stages-of-hiv-infection 2/6 Published: 13 July, 2012 Accesses 15 December 2020