South Tyneside
Safeguarding Children
and Adults Partnership

Safeguarding Adults Review

Adult AP

Overview Report

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Date: 30.12.2022

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1.0 Introduction

1.1 This overview report considers the sad circumstances of the death of Adult AP in November 2021. Adult AP was a lady of white British ethnicity who was aged 74 when she died.

1.2 Adult AP had been born in the North East of England but had lived in a number of different areas of the country throughout her adult life, however she returned to the North East and lived here for the last 30 years of her life.

1.3 Adult AP had worked as and IT lecturer at a local college before she retired, had enjoyed an active social life, hobbies including crafting, and had been an independent woman with 3 adult children living in the North East too.

1.4 In later life Adult AP suffered with significant pain from arthritis in her hip and knee joints which severely impaired her mobility. For the last few years of her life, she had been confined to sitting and sleeping in a recliner chair and was unable to access the bathroom in her property which was upstairs. In the last month of her life Adult AP developed serious pressure ulcers because of a rapid decline in her physical health.

1.5 This Safeguarding Adult Review (SAR) considers the circumstances leading up to Adult AP's death. The SAR will examine systems and multi-agency support that surrounded her to identify any learning that could improve services to others.

2.0 Context of Safeguarding Adult Reviews

2.1 The Care Act 2014 requires Safeguarding Adults Boards (SABs) to arrange a SAR if an adult (for whom the safeguarding duties apply) dies or experiences serious harm because of abuse or neglect and there is cause for concern about how agencies worked together. The SAR is conducted under Section 44(2) of the Care Act, based on the development of significant pressure ulcers to Adult AP's skin and the lack of multi-agency co-ordinated involvement following the implementation of a care package commissioned by the Local Authority a referral for a SAR was made.

2.2 Following discussion at the Practice Evaluation and Learning Subgroup (PEL) meeting in early 2022 the panel members agreed that the SAR threshold was met. The South Tyneside Safeguarding Children and Adults Partnership accepted this decision.

2.3 The STSCAP commissioned an independent author to carry out this review. The independent author is Michelle Grant who is wholly independent of the STSCAP and its partner agencies.

2.4 The purpose of SARs is '[to] *promote effective learning and improvement action to prevent future deaths or serious harm occurring again'.*[1]

[1] Department of Health, (2016) Care and Support Statutory Guidance Issued under the Care Act 2014 December 2022

2.5 The Department of Heath's six principles for adult safeguarding should be applied across all safeguarding activity.[2] The principles apply to the review as set out below:

Empowerment:	Understanding how Adult AP was involved in her care; involving those close to Adult AP in the review.
Prevention:	The learning will be used to consider prevention of future harm to others.
Proportionality:	Understanding whether services offered to Adult AP were proportionate to the risk of pressure ulcers she presented to herself.
Protection:	The learning will be used to protect others from harm.
Partnership:	Partners will seek to understand how well they worked together and use learning to improve partnership working.
Accountability:	Accountability and transparency within the learning process.

3.0 Terms of Reference

3.1 Adult AP is the primary subject of this SAR and the PEL members agreed the reviews aims and terms of reference for the independent author.

The review aims to:

Establish learning about the way in which local professionals and agencies work together to safeguard adults.

Highlight good practice and share this with the STSCAP

Identify any actions required by the STSCAP which will support and improve multi-agency working across systems and in direct practice.

Use the learning to reduce risks to others.

Terms of Reference
Was self-neglect recognised in this case?
What consideration had been given to the cause of self-neglect?
How did your engagement with Adult AP ensure a person led and outcome focussed approach?
How was the family engaged when Adult AP declined interventions?

[2] Ibid

Adult AP was deemed to have mental capacity to make informed decisions about her care, however many of these decisions were of concern. Was the ability of Adult AP to make decisions assessed or considered in terms of impact on safeguarding?
How did multi-agency partners work and communicate together to share their plans and concerns?

4.0 Methodology

4.1. The methodology applied to this SAR combined narrative reports which included chronologies from each agency which have been combined into key events leading up to AP's admission to hospital in November 2021 found at Appendix 1. The independent author and STSCAP Business Manager met with the adult children of Adult AP to establish their perspective and experiences of the agencies involved. This information as well as information provided to the report author from the agencies involved in supporting Adult AP was then applied to the 'fishbone' analysis tool found at Appendix 2.

4.2. Understanding the experiences of those receiving support from agencies is key to learning. The independent author would like to acknowledge her thanks to the son and daughters of Adult AP for their contribution to this SAR.

4.3. The privacy of the Adult AP and her family is protected in this SAR report using an alphabetical reference.

Agencies Providing Reports to the Review and Context of Involvement	
Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTWFT)	CNTWT is a Mental Health and Learning Disability Trust which provide the psychiatric Liaison Team that the STSFT staff referred AP to in November.
North East Ambulance Service (NEAS)	North East Ambulance Service covers the geographical area Adult AP's home was in and responded to calls from professionals and the care agency.
North Haven Care and Services Ltd (NHCS)	The agency provided care workers supporting Adult AP in her own home to manage some of her activities of daily living such as washing and dressing.
South Tyneside Council Adult Social Care (ASC)	Adult Social Care commissioned the package of care that Adult AP received in her home. They also provided the Social

	Worker (SW) and the Occupational Therapist (OT) input supporting AP.
South Tyneside Clinical Commissioning Group (CCG)	The CCG provided information and liaised with the GP surgery involved in supporting Adult AP.
South Tyneside and Sunderland NHS Foundation Trust (STSFT)	The Foundation Trust provided acute care whilst Adult AP was in-patient and also the District Nurses (DN's) and Acute Intermediate Care Team (AICT) staff who were attending AP in her home.

5.0 The Background of Adult AP

5.1 Adult AP was a woman of white British ethnicity. She was in her seventies when she died. Of the 9 protected characteristics[3] age and disability applied to Adult AP for the purposes of the review. There is no evidence to suggest that staff supporting Adult AP discriminated against her or that supporting policies and procedures would have excluded someone in their 70's. Adult AP did suffer from a 'disability' as defined under the Equality Act 2010[4] due to her limited mobility from chronic osteoarthritis and fixed flexion deformity of her neck. There is also no evidence in the information provided to the independent author to support that Adult AP was 'discriminated against' due her 'disability' either. Staff were actively encouraging her to be mobile and to access the community as far as possible.

5.2 As a primary school aged child, Adult AP had spent a prolonged period as an inpatient in hospital on 2 separate occasions receiving treatment for scarlet fever. As a result of infection control procedures at the time she was isolated from her family while in hospital.

5.3 This separation had a significant impact on Adult AP's psychological and emotional health, it resulted in her persistent fear of hospitals and medical staff. Throughout her adult life she had little cause to have to call upon health services, and during pregnancy gave birth to 2 of her children at home rather than in a hospital environment. Latterly she avoided accepting routine health screening offers and vaccinations.

5.4 The impact of this childhood trauma we would now recognise as an 'adverse childhood experiences'[5] (ACEs) although this is terminology that has only been used widely across professional agencies in the last 5 years.

[3] 9 protected characteristics: Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.
[4] Equality Act 2010 legally protects people from discrimination in the workplace and in wider society.
[5] Adverse Childhood Experiences are 'highly stressful, and potentially traumatic events or situations that occur during childhood and/or adolescence.

5.5 From 2018 Adult AP had suffered from significant limited mobility due to pain in her lower joints. This was formally diagnosed as osteoarthritis in 2020 and resulted in chronic pain limiting her mobility further.

5.6 Adult AP also suffered from a fixed flexion deformity which resulted in her head being permanently tilted towards her right shoulder. Her adult children describe this as something that their mother was very conscious of and made her less willing to be seen in public.

5.7 Those involved in the care of Adult AP, including her family, are all in agreement that these 2 hospital admissions as a young child were viewed by Adult AP as 'traumatic episodes' in her early life, her chronic pain also played a role in her decision-making ability.

6.0 Analysis and Learning

Analysis and learning have been identified using the fishbone analysis tool taken from the National Patient Safety Agency[6] (NPSA) toolkit. This was widely used prior to 1st June 2012 when the key functions of the NPSA were transferred to the NHS Commissioning Board Special Health Authority, later known as NHS England. The analysis tool still retains value in identifying clinical/service delivery problems. See Appendix 2 for the analysis tool breakdown.

6.1 Patient Factors

These consider clinical conditions and psychological factors.

Adult AP had been registered with her GP surgery from birth however her records are held electronically, for the purpose of this review her first contact was with the GP surgery in December 2019 when she sought consultation on an injured knee. It was noted at the time that she had a significant phobia of doctors and hospitals and had not been seen by a GP previously. Adult AP's reluctance to seek medical treatment and her need to prepare herself and build herself up to attend the Emergency Department or a hospital outpatient attendance was noted. She was felt by the GP to have the capacity to understand the risks to her health and the resulting outcomes of her decisions not to attend hospital, health screening appointments and flu vaccinations.

She was eventually able to attend for an x-ray and advanced degenerative changes of osteoarthritis in her hip were found. Whilst her fear of hospitals initially delayed the x-rays she was not refusing all offers of help and in March 2020 actively sought physiotherapy, consented to a referral to musculoskeletal services and pain management once the x-ray results were known.

Pain management was difficult, with the balance of pain relief by increasing dosages there were the risks of drowsiness leading to increased immobility. Regular movement was

[6] The National Patient Safety Agency (NPSA) was a special Health Authority created to co-ordinate the efforts of all those involved in healthcare, and more importantly learn from adverse incidents occurring in the NHS.

encouraged and advised, and information was given to Adult AP about joining the escape pain programme.

As Adult AP lived at home alone with support from her family safety concerns of increasing drowsiness were recognised, she was sitting in her chair most of the time and was beginning to struggle with meeting her daily living needs.

Equipment offered by the OT to support daily living needs was initially rejected by Adult AP but with repeat offers and explanations she would eventually accept these. When there were initial discussions with her about rearranging her sitting room to bring a bed downstairs she rejected the idea and described it as feeling like 'she was giving up', it may have seen as a constant reminder in the room she lived in that she was no longer the person she once was.

When discussing her care needs with the GP it was recorded that she found health professionals attending to her needs very hard to tolerate, and that she wanted to maintain her independence for as long as possible, even if this resulted in compromising her physical health.

Prior to admission to hospital Adult AP had said that she didn't want to die and did wish to be resuscitated, this information was considered by the GP when assessing her mental capacity prior to her hospital admission.

Whilst in hospital on the 26th of November Adult AP stated that she would 'just like it all to end' and that she would 'rather die than try and get treatment'. Both these statements are a clear indication of the state of mind and wishes of Adult AP in the last days of her life.

6.2 Staff Factors

These consider staff thinking, reasoning, and remembering.

Cumbria, Northumberland, Tyne and Wear NHSFT

STSFT staff assessed Adult AP on admission to hospital on the 25th of November 2021 and concluded that Adult AP's refusal of care was in part due to depression. They sought the advice of the Psychiatric Liaison Team (PLT) based within CNTWFT however staff here felt that due to the further deterioration in Adult AP's clinical condition it was not appropriate for this team to assess Adult AP. There was no further input into the care of Adult AP from CNTWFT.

North East Ambulance Service

On being called to Adult AP's home on the 17th of November 2021 the ambulance crew received a brief handover from NHCS staff which informed them that Adult AP had been sleeping in her chair for several months, that there was pressure damage to her skin and that she had not been eating and drinking and was refusing hospital admission and support with her care needs. The crew spoke with Adult AP themselves, discussing with her making a referral to ASC as they were concerned for her general wellbeing and notifying her GP. Adult AP refused sharing information with her GP and the referral stating she did not want

to bother people, especially overnight. When a pendant alarm was suggested, Adult AP again refused. During their conversations with Adult AP the crew felt they had no reason to doubt her mental capacity to make these decisions. Without Adult AP's consent the crew felt that they could not escalate their concerns further.

North Haven Care Services

When non-engagement was felt to be a problem by NHCS they escalated their concerns to the family of Adult AP on the 2nd of November, it was not until the 5th of November that they discussed these with their own General Manager. There was no contact to report these concerns to either Adult AP's GP or DN's by the care services staff or management themselves. The concerns weren't escalated to the SW until 12th of November when advice was sought about safeguarding concerns.

The family of Adult AP felt that some of the carers were better able to engage their mother in agreeing to let them care for her while others they felt may have been more inexperienced and less confident in their approach. Adult AP herself stated in comments made on 24th of November 2021 that carers had not been washing her or applying barrier cream. This statement infers that Adult AP would have accepted assistance and conflicts with the care records which demonstrate the care was declined on several occasions from 12th November onwards.

South Tyneside Council Adult Social Care

In June 2020 when a member of staff from the AICT spoke with a SW from ASC and was advised that the home circumstances were longstanding and that Adult AP had the mental capacity to make the decision to decline support, knowledge of self-neglect was recorded.

ASC staff recorded in the safeguarding documents that Adult AP 'is at risk of self-neglect and is refusing hospital treatment due to historic childhood trauma experienced in hospital. There does not appear to be any documented attempt to explore this with Adult AP or her GP to understand it in terms of Adult AP's behaviours and whether there were issues that could have been addressed or resolved. It was accepted as a fact that Adult AP would not agree to attend hospital and left at that.

Further there were other decisions that Adult AP took that resulted in significant harm from self-neglect, refusal to accept support with personal care and refusal to be transferred from her chair. This ultimately resulted in significant pressure ulcers which led to her hospital admission. There is no documented evidence that her rationale for these decisions was explored other than recording that she was 'in too much pain' and 'a private person'.

There was involvement of the Let's Talk Team when a safeguarding manager from ASC was present with the SW at the visit to Adult AP's home on 18th of November 2021 when it appears that safeguarding procedures were initiated following referral into safeguarding by the DN.

In early November 2021 when concerns about Adult AP's lack of engagement with her care was reported the ongoing management of her package was not discussed in the team daily

huddle where practitioners can bring cases they are working with to discuss complexities and challenges. The management of Adult AP was not discussed in supervision and not flagged to a senior manager within ASC until the day of hospital admission.

South Tyneside Clinical Commissioning Group – GP

There is no evidence provided for the purposes of this report that there was any professional curiosity about engaging discussing with Adult AP any type of therapy that she might have received historically to help her come to terms with her trauma or whether she would have engaged with any therapy in March 2020 to address some of her trauma experiences. The focus appears to have been on treating her clinical presentation and liaising with other professionals as necessary. Practice staff have received no training in relation to 'trauma informed practice' at the time of this report.

There was no evidence of discussion by the GP staff with their practice safeguarding adult lead as Adult AP's clinical condition continued to deteriorate during 2021. A safeguarding referral was not considered necessary by the GPs because of the number of agencies already engaged in the management of the care of Adult AP, despite the ongoing complexities of her care and the continued deterioration in her physical health.

The need to convene a multi-agency meeting was not felt necessary by the GP staff in 2021 until one was called on 17th of November by the DN service which a GP did attend.

On the 12th of November 2021 the GP was alerted to concerns over Adult AP's non engagement, she wasn't eating and drinking much and was not responsive to her medication with ongoing diarrhoea. An appropriate plan was put in place to try Imodium and encourage oral fluid intake and for telephone review after the weekend.

South Tyneside and Sunderland NHSFT

In the same way NHCS staff were unaware of Adult AP's childhood trauma and fear of hospitals and medical staff the AICT and DN service were also not informed. This information wasn't shared with them on referrals into their services by the GP or in any of the verbal communications between these staff and the GP and SW up to the point when the MDT meeting was called on the 17th of November 2021. The staff were attributing Adult AP's behaviours to her wanting to remain as independent as possible and the chronic pain, and later nausea and diarrhoea she was experiencing.

STSFT staff raised 2 safeguarding referrals about self-neglect and liaised with the internal safeguarding team to discuss their concerns on the 18th of November 2021. Advice and support were offered in relation to information sharing with relevant professionals. They were informed that ASC's safeguarding team were already aware. Further discussion took place regarding the need for an urgent MDT which the DN's organised. A discussion around AP's capacity took place and it was concluded without being formally assessed and documented that she had the mental capacity to refuse treatment. Advice was given to the DN's to raise a safeguarding referral. The safeguarding manager and designated nurse at the CCG were also made aware of the concerns.

The DN service were aware of Adult AP's lack of mobility and incontinence and could have reasonably expected her to be at high risk of developing significant pressure sores. The family managed to obtain photographs of their mother's sacrum on Monday the 15th of November and e-mailed these photographs to the DN service, it appears that it wasn't until 2 days later that the photographs were reviewed.

6.3 Task Factors

These consider guidelines and procedures as well as decision aids.

North East Ambulance Service

The ambulance crew attending Adult AP on 17th of November 2021 undertook a visual risk assessment of Adult AP's position following her slipping from her chair and recognised that in line with their procedures they would require the support of the evacuation team to safely transfer Adult AP back into her chair following her refusal of hospital admission.

At the time they recognised Adult AP's self-neglect under safeguarding procedures however following discussion with her they also felt she had the mental capacity to make decisions about her care. At this point it was not considered that they could make a safeguarding referral in Adult AP's best interest under duty of care to allow for a multi-agency risk assessment to be undertaken. They were provided with assurance from Adult AP that the DN's were coming the following day.

Normal practice for NEAS staff would be to complete a capacity assessment on a person if their capacity was questionable in relation to their ability to consent to transfer to hospital. On 25th of November 2021 Adult AP's transfer to hospital would have involved them assessing her mental capacity to consent to transfer from home to hospital. On this occasion when the crew arrived the decision to transfer had already been made by the GP under a best interest decision following assessment of her capacity. Adult AP did not appear to disagree with this decision when the crew arrived and as a result she was transferred to hospital.

North Haven Care Services

Self-neglect was recognised by carers following the first instance of refusal of care being noted on the 2nd of November 2021. As a result they contacted the daughter of Adult AP who confirmed that the GP was due to complete a pain management review with Adult AP.

Despite Adult AP appearing to have capacity to refuse care safeguarding concerns were raised around self-neglect with the Let's Talk Team at ASC and the SW on the 12th of November 2021. The carers sought advice and guidance in relation to refusal of care/support of nutrition, concerns raised by Adult AP's family about her lack of engagement, as well as refusal of hospital admission and treatment from the DN's. While there was no reference made by the care staff to the self-neglect toolkit, they clearly felt that their concerns were of a serious nature.

NHCS staff training is delivered in a person-centred manner so that care staff understand that gaining a person's consent, respecting a person's right to choose and also their right to refuse is embedded in the principles of the Mental Capacity Act.

NHCS carers attempted on each visit to provide personal care due to increasing concerns around the development of pressure ulcers. Carers were not aware of any mental health diagnosis for Adult AP and there was no reason for them to raise concerns under the Mental Health Act.

Advice and guidance in relation to safeguarding, capacity and any court of protection intervention were raised with the SW on the 12th of November.

South Tyneside Council Adult Social Care

Mental Capacity was considered by the SW at various stages throughout their involvement, being referenced in the case notes that Adult AP had the mental capacity to make decisions relating to refusal of interventions and hospital admission. However, no formal capacity assessments were documented by the SW and not when it was documented on the 12th of November 2021 when they questioned whether non-engagement of Adult AP was due to her actual choice or because AP was now too drowsy and unwell to make coherent decisions. The STSCAP safeguarding policy refers under section 5 Mental Capacity to '*when a person's self-neglect poses a serious risk to their health and safety, intervention will be required. Prior presumption of mental capacity may be revisited in self-neglect cases. There may be cause for concern if a person repeatedly makes unwise decisions that put them at risk of harm or exploitation or makes a decision that is obviously irrational or out of character. Further exploration of past decisions and choices would need to be undertaken at this time'.* Importance was placed on Adult AP's right to make her own decisions under Article 8 of the Human Rights Act 1998[7].

There is no evidence that AP's mental health was discussed with her directly by the SW however there are references to discussions with her daughters stating that they felt their mother had just 'given up' and that the situation was not usual for their mother. There was reference to Adult AP having a fear of hospitals, however this appears to have been accepted as such with no consideration of addressing the issue and the impact this may have had on Adult AP's mental health and/or decision making. No consideration was given to whether psychological assessment or support could have been discussed with Adult AP or her GP.

It does not appear that the SW considered discussing Adult AP with the Local Authorities Let's Talk Team who are the lead coordinating agency for all complex multi-agency safeguarding adults' processes. The STSCAP policy and procedures do not appear to have been referred to, there are several documents available to support staff including the self-neglect screening tool and the risk threshold tool respectively. Had these been referred to at the beginning of November 2021 when Adult AP's daughter spoke to the SW about the family's and carers concerns that Adult AP was refusing care she would have met the criteria

[7] Article 8 protects your right to respect for your private and family life.

for 'person to be referred for section 42 enquiry' on the self-neglect screening tool, and 'high risk' on the risk threshold tool.

South Tyneside Clinical Commissioning Group – GP

From a review of the NICE guidance on the management of osteoarthritis[8] it is evidenced that the GP staff largely managed Adult AP's chronic health condition in line with the guidance at the time. She had medication reviews and her consent was obtained to refer her to musculoskeletal services and pain management, via the escape pain programme. Adult AP was given encouragement to increase her movement and mobility.

No formal risk assessment or documented pain management plan was recorded to highlight the increasing concern about Adult AP's non-engagement with treatment which could have fed into an earlier practice 'high risk' meetings or discussion with the practice safeguarding lead.

The practice advised that they would consider using the self-neglect resources and toolkit provided by the STSCAP in situations where they were suspecting self-neglect and appropriate agencies were not already involved.

In June 2020 Adult AP was visited at home by a GP at which her living conditions were already described as 'bad'. She was spending all her time in a chair in the sitting room being lifted on to the recliner chair for 'bed'. Adult AP was showing signs of being unable to manage her hygiene, using wet wipes, not having bathed or showered for some months and rarely changing clothes. Her home environment was deteriorating with an unpleasant smell and soiled carpets. Whilst not described as 'self-neglect' in the GP record they recognised the deterioration but no safeguarding referral for self-neglect was considered or discussed with Adult AP at this time. The action was to contact the DN's and for the daughter to contact ASC. This was a missed opportunity to discuss safeguarding with Adult AP to establish her views, and to have discussed her care at a practice 'high risk' meeting and with their own safeguarding lead.

Adult AP was kept at the centre of decision making and her views were always sought in relation to her medical care. There was attention given to both her rights under the Mental Capacity Act as well as consideration given to her Article 8 rights under the Human Rights Act.

South Tyneside and Sunderland NHSFT

The District Nursing Team were first aware of Adult AP in June 2020 when the GP referred Adult AP to them following their visit to her home. At this time a member of staff from the AICT spoke with a SW from ASC and was advised that the home circumstances were longstanding, and that Adult AP had the mental capacity to make the decision to decline support, therefore no DN support was felt necessary at this time.

During their home visit in June the AICT staff documented that there was a strong smell of urine in Adult AP's sitting room. Adult AP had been urinating in a bowl at the side of her

[8] National Institute for Health and Care Excellence Osteoarthritis: care and management December 2022

chair, she had a commode which she stated was too high for her to use. An alternative commode was offered however Adult AP refused this, preferring to use the bowl. Adult AP did consent to a continence assessment during this visit and staff discussed the different continence aids all of which Adult AP refused. They discussed skin integrity and how this could be compromised and offered a pressure area check which Adult AP refused. Staff felt Adult AP had the mental capacity to make these decisions so respected her choices.

Adult AP's self-neglect was recognised by the agencies supporting her. Professionals and carers working with Adult AP recognised that she was neglecting to care for her personal hygiene and surroundings in large part due to her immobility and chronic pain. In line with the current MCA Code of Practice staff did not feel they needed to record formal mental capacity assessments on Adult AP in relation to her ability to give her informed consent to her care when she was able to demonstrate that she could retain information, understand the risks of non-engagement, and give a coherent answer to what care she would and would not accept.

The Trust does not have a non-engagement policy to support staff in the community managing people who self-neglect and refuse services. However, it is standard practice that District Nurses will offer an alternative appointment if patients refuse or cancel visits as evidenced on the 10th of November when AP refused a visit but agreed to be seen the following day.

The DN's recognised that although low in mood due to her chronic pain Adult AP did not require an assessment under the Mental Health Act, her problems were related to her physical health and not her mental health.

Staff caring for Adult AP at the acute hospital were aware of self-neglect being the reason for her hospital admission. Based upon her presentation, clinical staff and the family made the decision that Adult AP would be more appropriately cared for using a palliative care approach to keep her comfortable in the last stages of her life.

6.4 <u>Communication Factors</u>

These consider all forms of communication verbal/non-verbal, written and its management.

North East Ambulance Service

No issues have been identified.

North Haven Care Services

NHCS were unaware of Adult AP's hospital experiences as a child resulting in long term trauma and fear of hospitals and medical staff until the safeguarding meeting. When they discussed Adult AP's non-engagement with her she informed them that pain prevented her being more accepting of their help. The conversations were not expanded upon or explored further.

When they were contracted to deliver the care package this history of trauma could have been useful to them. When they did engage with Adult AP over her refusal of care this was

attributed by Adult AP to the pain she was suffering. The DN's were also in attendance at some of these interventions and were also unaware of Adult AP's past trauma.

When Adult AP lost weight her hoist straps were too big for use by carers, this does not appear to have been reported to the OT at the Local Authority to allow for smaller straps to be ordered to assist in moving Adult AP.

From the 12th of November Adult AP's care plan has pressure area checks added to it in addition to meeting her personal hygiene needs. Adult AP's family photographed the significant pressure ulcers on Adult AP's sacrum on the 15th of November. Care records demonstrate from 13th of November 2021 to 25th November 2021 Adult AP refused pressure area checks on 6 occasions, once on 17th it is recorded that her family had checked her pressure areas and on a further 6 occasions it is recorded that Adult AP's skin was red and sore. It is not clear whether ASC and DN's were made aware of these findings on each occasion to allow for a pattern to be established. It was documented that the DN's would attend on Tuesday's and Thursday's at midday to assess pressure areas from 16th of November onwards, this should not have prevented the care provider from sharing daily updates as required.

South Tyneside Council Adult Social Care

As previously noted ASC staff did not communicate Adult AP's past trauma to NHCS when the care package was commissioned. Whether this was due to poor communication between the SW and the contracting team or poor communication between them and NHCS is not clear.

There was no communication back to NHCS staff following their wanting to discuss a safeguarding referral in respect of Adult AP's non-engagement with her care package on Friday the 12th of November. They had to contact the SW again on the 17th of November when they were at Adult AP's home and she was found to be in an awkward position on her chair, staff had to call for ambulance assistance to reposition her because she had refused assistance from the carers due to her level of pain and general poor health. The SW apologised for the delay in updating in carers about actions, she had been on a few days off and this concern had not been passed to a colleague to assess and feedback.

There was a lack of communication with the GP and DN on the 2nd of November when NHCS staff alerted the SW to their concerns about Adult AP's non-engagement. The GP was not aware of this until they attended a planned home visit on the 9th of November to undertake a medication review. The GP was not contacted by the SW until the 12th of November to alert them to these concerns. It was also the GP that alerted the DN's that their input was required again following their home visit on the 9th of November.

It is not evident that the SW discussed the comments made about the carers by Adult AP on the 24th of November or established clearly what care was not being delivered by the carers when they raised their concerns with the SW on the 2nd of November 2021.

South Tyneside Clinical Commissioning Group – GP

The referrals made into the DN service by GP staff did not alert the team to the fact that Adult AP had a significant fear of hospitals and medical staff following traumatic admissions to hospital as a small child.

There was good engagement by the GP in the MDT meeting on the 17th of November and relevant information and concerns were shared. The GP led these meetings however minutes with actions and leads identified were not formally recorded. The DN could not attend the MDT hence held a catch up session afterwards with the SW/OT and GP. [**Recommendation 4**]

South Tyneside and Sunderland NHSFT

The DN team can communicate with GP surgeries electronically via EMIS allowing primary care staff to be notified of any changes in patient presentation and in the case of Adult AP her non-engagement with their service.

There were attempts made by the DN service to communicate with the care agency staff and Adult AP to try to ensure she had taken pain relief medication ahead of their visits in an attempt to promote better engagement with meeting her care needs however this was not always successful.

There were some concerns raised from the family in relation to aspects of care not being accommodated by hospital ward staff. This was due to the rapid decline in Adult AP's condition, and it would have been unsafe to do so.

6.5 Resource Factors

These consider the availability and use ability of equipment and are considered below for the agencies affected.

North East Ambulance Service

On the 17th of November when NEAS were called to the home of Adult AP because she had fallen out of her chair the crew requested the back up from the evacuation team to support safe moving and handling. At this time one vehicle was off the road and the second was in the South of the County. As a result a second crew were dispatched, both crews used equipment available to them to move Adult AP back onto her chair. This did not result in any further decline in Adult AP's already poor physical health.

North Haven Care Services

The stand aid sling had proven to be to big following Adult AP losing weight, there was a delay in reporting this to the OT so that a new moving and handling assessment could be undertaken, and new equipment being provided.

There were not felt to be any resource factors identified by any other the agencies for the purposes of this SAR Overview Report.

6.6 Working Conditions

These consider environment and staffing

North East Ambulance Service

There were no conditions which had a negative impact on the ambulance services ability to care appropriately for Adult AP when they attended her home and when she was transferred by them into hospital.

North Haven Care Services

Although the home of Adult AP was described as malodorous at times the care staff attending Adult AP continued in their attempts to support her and encourage her to accept their help. There is no evidence to suggest that there were any staffing shortfalls in providing care to Adult AP as commissioned by the Local Authority.

South Tyneside Council Adult Social Care

There were no conditions which had a negative impact on the Local Authority's ability to provide care to Adult AP. The OT was actively engaged in supporting Adult AP to live in her own home for as long as possible in comfort and provided supportive equipment when Adult AP gave her consent to accept this.

South Tyneside Clinical Commissioning Group – GP

In the first lockdown from March 2020 until easing of some restrictions general practice reduced the amount of face-to-face contact with patients in line with government legislation. It is noted in early 2020 contact between Adult AP and her GP was via telephone which appears to have been acceptable given that significant concerns about the decline in her physical health did not escalate until 2021.

South Tyneside and Sunderland NHSFT

The DN Service was not compromised in their ability to care for Adult AP throughout the Covid 19 pandemic, the working environment was at times described as malodorous, but this did not impact on the continuing support the DN's provided to Adult AP with her consent.

6.7 <u>Organisational Factors</u>

These consider organisational structure and safety culture where applicable

North East Ambulance Service

The organisational structure and safety culture at NEAS had no impact on the care the ambulance service delivered to Adult AP in the minimal contact they had with her. It is not clear whether when the ambulance crew arrived, they were aware that the family's view of the transfer to hospital conflicted with that of the professionals and whether the crew would have raised this with professionals in Adult AP's home at the time of transfer had they known. The GP was the decision maker at this time.

North Haven Care Services

North Haven Care Services received a CQC overall rating of good on 25th June 2021[9]. In all 5 areas the inspection looked at; safe, effective, caring, responsive and well-led they were reported as good.

South Tyneside Council Adult Social Care

There are clear organisational structures within the Local Authority which staff involved in the case management of Adult AP were aware of. There were clear cumulative patterns of self-neglecting behaviour that Adult AP was demonstrating, and which were resulting in significant harm to Adult AP and whether the effects of the pain relief were making Adult AP so drowsy that her ability to retain and weigh up information and make an informed decision was not discussed with other professionals outside ASC or with safeguarding managers within ASC. No safeguarding procedures were instigated by either the SW or the OT until actioned when the DN's referred on 18th of November at which stage Adult AP had suffered significant harm.

An overprotective safety culture does not appear applicable in the management of Adult AP, rather there was an over optimistic belief that with the right support and pain relief Adult AP would be able to prevent a deterioration in her physical health.

South Tyneside Clinical Commissioning Group – GP

The organisational structure at the GP surgery is left to the GP partners and practice manager to agree. There is a recognised safeguarding lead at the practice and a process for discussing high risk cases. There is no evidence to support that Adult AP was ever discussed at a high-risk meeting within the practice.

There is no evidence of an overly protective safety culture from the GP's involved in supporting Adult AP in the community. There is clear evidence that they spent considerable time engaging Adult AP in discussing what her health problems were and how these could be addressed. Offering her choices over medication and referrals to other agencies. When on 15th of November Adult AP expressed that she did not feel morphine was helping her pain management it was agreed to revert back to Codeine and add in Amitriptyline, not for its antidepressant effect as Adult AP had refused previously but for its pain relief benefit.

At the point that professionals gathered in Adult AP's home with her family to discuss with her and her son and daughters the acute nature of her presentation on the 25th of November the GP made the decision to complete a formal mental capacity assessment on Adult AP. At this point despite Adult AP stating she still didn't want to go into hospital and her family agreeing their support for her in this decision it was felt that a formal assessment of Adult AP's mental capacity was now necessary. In line with the current Mental Capacity Code of Practice the GP made the decision to admit Adult AP concluding that she was not able to understand the severity of her clinical presentation and that attempting to meet her wishes to be cared for in the community was no longer possible. The best interest decision

[9] Northhavencs.co.uk

was made in good faith and in what was believed to be the best way of assessing her current state of health.

South Tyneside and Sunderland NHSFT

There is a clear organisational structure within the hospital that staff were aware of, they have access to a safeguarding team for advice and support and can access safeguarding supervision if requested.

There is a safeguarding policy which all staff are expected to refer to if required.

Due to the short timeframe in which Adult AP was in the care of the hospital there was appropriate management oversight of her care and treatment, the hospital did liaise and consult with the PLT. There were no organisational structure failings felt to have impacted negatively on Adult AP's care.

The family of Adult AP shared their concerns in relation to the way the care of their mother was delivered. They would have wished for consideration to be given to returning their mother home to die when it was clear that she was not going to survive. Both they and she had expressed that she did not want to die in hospital prior to her admission. The family feel that this was not explored in sufficient depth by the hospital staff, and they are left feeling that their mother died in a place she never wanted to be, and that they have failed her. However, Adult AP deteriorated very rapidly to a point where it would have been unsafe to transfer her back home.

The DN's were respectful of Adult AP's autonomy and right to self-determination. They were confident in their clinical roles and acknowledged that they could only treat Adult AP with her consent. They shared their concerns with Adult AP and her family as well as with other professionals and recognised when the risks were escalating. It was the DN service out of all the agencies working with Adult AP in the community that raised the initial safeguarding referral. They had reached a point when they recognised that they had a duty to act which they informed the SW of when they were informed by this member of staff that NHCS were reporting daily that Adult AP was declining personal care but she had the capacity to do so. The DN's felt they had a duty to support with changing Adult AP's incontinence pads and cleaning her skin at each daily visit. They also informed the SW that following an explanation of how important this care was Adult AP gave her consent.

The first safeguarding adult referral was made to ASC about Adult AP on the 19th of November 2021 and the second on the 25th of November 2021. The first referral was made under the category of self-neglect and provided the following information:

Adult AP had been sitting in a chair for 4 days in her own urine and faeces and without any personal care or pad change being provided. Has extensive pressure/skin damage to buttock/legs. Also has skin damage to buttock/coccyx/legs. Also has a skin infection to the neck, hard thick plaques to both legs. Adult AP has carers who visit daily, Adult AP's daughter had identified a left buttock wound and DN's were not informed of this for several days. The GP had made a referral for DN's to visit Adult AP for pressure damage, Adult AP declined the DN's review of her skin for several days. Adult AP was reviewed by GP and

declined any medical intervention (deemed by GP to have capacity) and not taking diet only fluids. Adult AP informed by the GP of the consequences to health by declining intervention.'

The second referral on the 25th of November 2021 was also made under the category of self-neglect. It detailed a similar picture to that above but included a written description of the extent of the pressure damage to Adult AP's skin and the high likelihood that there was infection present in the wound due to the malodour of it and the presence of necrotic tissue.

On a review of the records by the Trust it was evident that staff considered 'Making Safeguarding Personal' in that Adult AP was fully engaged in decisions relating to her care. Her wishes and choices were considered, albeit some of these may be felt to be 'unwise' choices, for example her refusal of pressure relieving equipment and pressure area checks. On these occasions a mental capacity assessment was considered however one was not felt necessary because it was documented that Adult AP was deemed to have capacity.

Adult AP refused an assessment of her pressure areas by the DN's on the 10th of November 2021 until she had better pain relief, and this decision was respected by the DN's as there was no reason for them to believe Adult AP did not have the capacity to make this informed choice.

There was no evidence of a safety culture that was paternalistic in its response to Adult AP during the time periods that the DN's were actively engaged with Adult AP.

6.8 Education and Training Factors

These consider competence and supervision.

Cumbria, Northumberland, Tyne and Wear NHSFT

Staff receive mandatory adult safeguarding training commensurate to their role which is compliant with the requirements of NHS England's Intercollegiate Document of Safeguarding Guidance, and which is Care Act compliant and highlights self-neglect as a category of abuse.

North East Ambulance Service

The ambulance staff agreed that Adult AP had significant health needs which she was not fully engaging with when they attended her home on 17th November 2021. She shared with them her fear of hospitals and that she didn't want to bother people. She refused to allow them to speak with her GP to be referred for blood tests and advised them that the DN was visiting the following day. Adult AP was found to hold a conversation well and the crew concluded that she was making an informed unwise decision.

Consideration could have been given to override her decision if this had been deemed to in the wider public interest, as it was not the crew did not make a referral. The crew were mindful of respecting Adult AP's Human Rights under Article 8 as well as her Article 2 rights the Right to Life. Balancing the persons autonomy against the professional duty of care was a recurring theme in how agencies engaged with Adult AP.

When NEAS were called back to Adult AP's property on the 25th of November to transport her to hospital they were aware of the best interest decision that professionals had discussed and agreed with the GP that it was in her best interests to no longer remain at home they respected this decision as being in accordance with the Mental Capacity Act.

No senior support was sought by the ambulance crews in their engagement with Adult AP, had they felt they needed to discuss their concerns within their own organisation there is a route for them to do this that staff are aware of, and is covered in their safeguarding training.

North Haven Care Services

NHCS staff agreed with each other over Adult AP's mental capacity to refuse care and treatment, and their management team were aware of this. The level of training provided to the care staff by NHCS met the standard required to be a provider of care that the Local Authority commissioned.

South Tyneside Council Adult Social Care

ASC staff must undertake mandatory training commensurate to their role and this includes legal literacy and safeguarding training, including revisiting safeguarding policy and procedures and the self-neglect toolkit.

Staff have access to reflective supervision and can request urgent discussion of cases with a senior manager if required.

It is unclear what action the SW took in response to her comment to the DN's on 25th of November that the care agency were reporting daily that Adult AP was declining personal care and whether on any of these occasions the SW had documented that they would need to undertake a further capacity assessment on Adult AP.

South Tyneside Clinical Commissioning Group – GP

General Practice staff receive mandatory adult safeguarding training commensurate to their role which is compliant with the requirements of NHS England's Intercollegiate Document of Safeguarding Guidance, and which is Care Act compliant and highlights self-neglect as a category of abuse. They also have access to the Partnership Boards policy and procedures and the self-neglect toolkit. As described at 6.3 GP (page 13) self-neglect was recognised but safeguarding was not triggered because the focus was on managing the physical health needs of Adult AP.

The GP staff also agreed with other professionals that Adult AP had the mental capacity to understand her care needs and the risks of not having these met.

South Tyneside and Sunderland NHSFT

Staff at the hospital have their own internal safeguarding team contactable by a Single Point of Contact (SPOC), and although not mandatory via intercollegiate document requirements, supervision is provided as best practice with the DN teams on a 6 monthly basis. There is

also a clinical and a safeguarding supervision policy. The safeguarding team provide visibility to both A&E and EAU staff daily Monday-Friday to discuss any safeguarding issues.

Due to the short time frame that Adult AP was in the care of the hospital staff there are no areas that have identified competence problems, and there would have been no timeframe to review the care of Adult AP during a staff supervision session.

Within STSFT mandatory training and via safeguarding supervision staff are encouraged to seek advice from the legal team when dealing with complex patients/self-neglect to consider Court of Protection applications. The legal team have a close working relationship with the STSFT safeguarding team. STSFT felt that following review of records relating to Adult AP that there was not a requirement for the team to have sought legal advice in respect of Adult AP, however this would have been considered as an action had she not been admitted to hospital and there were concerns regarding further engagement with care interventions.

6.9 Team Factors

These consider how staff perform in their roles as a team and leadership

North East Ambulance Service

The ambulance crew attending Adult AP on the 17th of November correctly recognised that they would benefit from the support of their evacuation team and sought their assistance appropriately. No leadership issues have been highlighted.

North Haven Care Services

The carers attending Adult AP visited in 'pairs' they took responsibility for supporting her with washing and dressing, meal preparation and medicines administration. Information about AP's refusal of care was escalated up to managers within the agency.

South Tyneside Council Adult Social Care

There is no doubt that the SW was aware of each agencies role in supporting Adult AP and there were frequent telephone calls between professionals. Had there been earlier review of the partnership's self-neglect toolkit which would have prompted safeguarding procedures then there may have been better coordination of communication and information sharing between agencies.

As lead agency for safeguarding ASC did not pick up the leadership role in the management of Adult AP until the referral was made by the DN's on the 19th of November 2021. Had the SW not deferred the safeguarding concern of NHCS staff on the 12th of November 2021 to assess Adult AP themselves and speak to the GP when there was already clear evidence of high risk an earlier meeting could have been coordinated and a comprehensive risk assessment and action plan been put in place.

Given the severity of Adult AP's pressure damage by the middle of November it cannot be concluded that a safeguarding meeting on this date or the day after could have been attended by all relevant staff or would have led to a different outcome for Adult AP. At this

point it was felt by all professionals and Adult AP's family that she still had the mental capacity to refuse treatment. A documented assessment of her mental capacity in this regard would however have been best practice, with capacity assessments being revisited at each refusal of care to build up a picture.

South Tyneside Clinical Commissioning Group – GP

The GP's involved in the care of Adult AP coordinated with other health colleagues to support Adult AP's health needs. There is no evidence to suggest that the GPs sought support from their own safeguarding lead who might have provided some leadership or direction in terms of earlier safeguarding support or advice on whether overriding her refusal of care would have been possible. Neither was her lack of engagement nor increasing risk of serious deterioration discussed at a high-risk meeting within the practice.

South Tyneside and Sunderland NHSFT

The DN's were clear in respect of what their role was and tenacious in their attempts to engage Adult AP in accepting their offers of support. They coordinated well with the OT in managing to transfer Adult AP to the hospital bed in mid-November 2021. There is also evidence of them taking a leadership role in discussing Adult AP's care at the huddle on the 18th of November 2021 and advising that risk assessments were required.

The medical team sought the support of the PLT when it was considered that Adult AP's presentation could be linked in part to depression. No leadership issues have been highlighted.

7.0 Good Practice

7.1 North East Ambulance Service

7.1.1 Despite the evacuation team not being available to support the ambulance crew in moving Adult AP back onto her chair they sought the support of another ambulance crew and working together the 2 crews did manage to reposition Adult AP back onto her chair.

7.2 North Haven Care Services

7.2.1 Despite not knowing the full background of the adult they were supporting NHCS staff built up what they believe to be a good working relationship with Adult AP and her family over the 14 months they were supporting her. They regularly reinforced the professionals' messages about the risks to her physical health of her refusal of care. They followed the MCA Code of Practice in assuming Adult AP had the mental capacity to make decisions about what care she would accept and followed their training in delivering a person-centred approach.

7.2.2 Carers escalated the non-engagement of Adult AP to their management and shared this with the family. The management at NCHS also made ASC aware of the concerns of their staff about the non-engagement of Adult AP.

7.3 South Tyneside Council Adult Social Care

7.3.1 The SW maintained contact with Adult AP and her family when her care needs were being reassessed. Both Adult AP and her family's perspectives on what care support and equipment was required or would be accepted was addressed promptly by both the SW and the OT.

7.4 South Tyneside Clinical Commissioning Group – GP

7.4.1 The GP spend over 3 hours with Adult AP on the 25th of November the date of her transfer into hospital. They took the time to liaise with other professionals and to seek to understand Adult AP's views in respect of her refusal to accept medical support. The views of Adult AP's family were also taken into consideration as was advice from a psychiatrist. The GP ultimately made the decision in good faith that Adult AP at this time lacked the insight into the severity of her risk of death if she wasn't at least assessed fully by hospital staff. Best interest principles were followed, and ambulance transfer was requested.

7.5 South Tyneside and Sunderland NHSFT

7.5.1 On the 18th of November 2021 when the extent of the pressure damage was apparent, a hospital bed had been agreed to by Adult AP and was delivered, good team working is identified, the DN's worked alongside the OT's and Carers to transfer Adult AP safely from her recliner chair on to the bed to allow for better wound management and position changes.

7.5.2 Throughout November 2021 the DN's were persistent in their approach to Adult AP's care. They constantly reinforced their concerns to both Adult AP and her family of the risks associated with the 'unwise' decisions Adult AP was making. They also highlighted to the SW that they had a duty of care to Adult AP and could not leave her saturated in urine and faeces and that when they discussed this with Adult AP she would allow them to support her with hygiene needs.

7.5.3 In November 2021 the DN team contacted the Trust safeguarding team to discuss and reflect upon Adult AP's presentation. It was confirmed that a safeguarding referral needed to be submitted for Adult AP under the category of self-neglect, 2 were made.

7.5.4 All professionals took the trouble to share information both verbally and in written form to allow Adult AP to be empowered to make informed decisions about what care and treatment she would accept.

8.0 <u>Practice Areas for Development</u>

North East Ambulance Service

The service may want to use the findings from this SAR report as a learning opportunity for staff in relation to the balancing of respect for the persons autonomy against the duty of care. Cases of self -neglect where there is no evidence of an impairment of the persons mental capacity are a challenge and staff working out in the community will come across this more frequently than hospital-based staff.

North Haven Care Services

Following the contact made by carers on Friday the 12th of November to ASC to discuss a safeguarding concern and being informed on that date that the concern would be 'paused' until the SW had completed her assessment and spoken to the GP. The Care Service has reflected on this and feel that a formal safeguarding notification via ASC's Let's Talk Team may have been more appropriate given how high risk the decline in Adult AP's health was and her non-engagement was not likely to change in the immediate future. Learning from this case has been shared across NHCS.

All employees with NHCS attended and completed a significant amount of training courses including, safeguarding, Mental Capacity Act and Deprivation of Liberty Safeguards and the importance of reporting and recording information at the beginning of 2022 to ensure all employees are up to date with current legislative requirements and refreshing knowledge in these key areas. This training is also offered to office-based staff who are also attending.

Following reflection on the care given to Adult AP by the service the South Tyneside self-neglect and Hoarding Toolkit is now part of NHCS training to raise awareness and identify these areas.

South Tyneside Council Adult Social Care

Workforce development in relation to self-neglect and safeguarding is currently being reviewed by ASC.

Workforce development is being undertaken in relation to understanding of the Mental Capacity Act and the impact of previous decision making.

Workforce development in relation of appreciative enquiry with a focus on decision making and safeguarding is also being undertaken.

Reflective supervision; there is implementation of a new policy, tools and templates to include reflective discussion about all active cases. A supervision quality assurance process which includes audit and observation is due to be implemented from April 2022

Practice Supervisors Standards (Skills for Care) is due to be implemented between April 2022 – September 2023.

South Tyneside Clinical Commissioning Group – GP

Highlighting the role of the practice safeguarding lead to all practice staff and to have a process to include recording of the discussion held and actions in this respect within with persons GP record. Increasing the awareness and value of the high-risk meetings across Primary Care and have a process to ensure that these discussions and actions are also recorded and held within the person's GP record.

Review the use of Emergency Health Care Plans to ensure that the wishes of people are respected when they have capacity. The independent reviewer is respectful of the GP's decision at the time of Adult AP's admission to hospital when given the evidence at the time the GP concluded that Adult AP lacked the mental capacity to understand how critical her condition was felt to be and a best interest decision was made.

South Tyneside and Sunderland NHSFT

Both the DN team and EAU hospital staff have received safeguarding supervision from the safeguarding team with regards to self-neglect following initial learning from their care of Adult AP.

Senior managers at the Trust are in the process of developing the community electronic EMIS system to enable MCA assessments to be accessed readily on EMIS. Currently DN's must access the MCA template through the Trust intranet, complete and then upload completed assessments onto EMIS.

The Trust may want to use the findings from this SAR report as a learning opportunity for staff in relation to the balancing of respect for the persons autonomy against the duty of care. Cases of self -neglect where there is no evidence of an impairment of the persons mental capacity are a challenge and staff working out in the community will come across this more frequently than hospital-based staff.

The trust have reflected on whether it would have been possible to transfer Adult AP back to her own home to die as she had previously expressed her wishes to be. Adult AP's condition deteriorated rapidly on the 2nd day of her admission. There were discussions with the family about ongoing medical interventions and whether this was in her best interests. It was agreed that the appropriate course of action was no withdraw treatment and keep Adult AP comfortable given that her prognosis was so poor. This allowed the family to spend time with Adult AP with only minimal disruption from staff until she died peacefully.

To support community-based staff the Trust may wish to consider the development of a Non-engagement Policy to support staff in relation to safeguarding when people consistently refuse offers of service. The independent author notes that the Trust have stated that when refusal is made further offers of visits will be offered, however if these are repeatedly refused a link between this and self-neglect under 'safeguarding' may be useful. There are good examples of non-engagement policies available online.

9.0 Conclusions

9.1.1 Professionals providing services and support to Adult AP have a duty of care[10] to that person. The DN staff clearly recognised this on their visit to Adult AP on the 18th of November following Adult AP declining care and support on 3 earlier visits from the 10th of November. On this occasion they sought and obtained Adult AP's consent to submit a safeguarding referral to allow multiagency information sharing and risk assessment.

9.1.2 Safeguarding is everyone's responsibility[11]. Agencies did consider safeguarding however it was only the North Haven Care Service staff who discussed safeguarding directly with the SW on the 12th of November but at this time they were advised to 'hold off' to

[10] The "**duty of care**" refers to the obligations placed on people to act towards others in a certain way, in accordance with certain standards. In the DN staff the NMC Code of Practice.

[11] Local Government Association Safeguarding means protecting people's right to live in safety, free from abuse and neglect.

allow for more information gathering. The DN triggered safeguarding procedures via submission of a safeguarding referral. A 2nd safeguarding referral was submitted by STSFT acute staff on the 25th of November.

9.1.3 When the care provider queried safeguarding with the SW on the 12th of November and was advised to hold off the safeguarding referral because the SW wanted to obtain further information. This was an unfortunate delay and a missed opportunity to bring professionals together to discuss the management of Adult AP in the community with risks being identified and mitigated as far as possible by those best placed to do so. Legal advice could have been considered once all current information was known.

9.1.4 At the visit on the 23rd of November both the SW and the Operational Manager were present in the home of Adult AP and concluded that no safeguarding process was required. This decision appears to have been taken without reference to the self-neglect toolkit which if applied to the information known about Adult AP would have indicated that safeguarding procedures should have been instigated.

9.1.5 Adult Social Care are the lead agency for safeguarding under the Care Act 2014 and have a responsibility to undertake investigations into self-neglect. Adult AP's was a complex case and would have benefitted from earlier senior oversight as the poor engagement with care provision continued and the risks escalated.

9.1.6 At the practitioner learning event staff were definitive in their views that Adult AP's was not an exceptional case and that self-neglect and non-engagement were the most common cases that they come across in the community. They were clear that there needed to be a greater awareness and use of the STSCAP's existing self-neglect toolkit available to all agencies.

9.1.7 At the learning event most staff also identified that stronger support for multi-agency working, and supervision would make risk management and safety planning more robust. The use of single agency huddles for information sharing was not as effective as having a formal multi-agency risk management (MARM) meeting structure supported by the agencies who attend the STSCAP with leads in their own organisation identified for supporting such meetings. Practitioners attending the learning event were clear that MARM meetings would support them in their work with people who self-neglect or where non-engagement is identified when safeguarding procedures are not yet instigated.

9.1.8 Staff reported back at the learning event that they felt it could be lack of confidence that prevented staff from escalating issues to senior managers and not having the time to ask for supervision due to workload pressures. **[Recommendation 7]**

9.1.9 It is important that staff feel supported to manage complex cases and can raise their concerns when people fail to engage with their care and support which will lead to the risk of significant harm. All staff must be empowered to put knowledge and skills acquired in training into practice. **[Recommendation 7]**

9.2 Policies and Procedures

9.2.1 All staff involved in the care of Adult AP have access to the STSCAP's safeguarding adults' policy and procedures. They also have access to their own agencies safeguarding adults' policy and procedures. It is evidenced in the report that not all staff referred to these policies and procedures during the time they were supporting Adult AP. The policies demonstrate that self-neglect is a category of abuse under the Care Act 2014, and the report identifies those professionals recognised increasing self-neglect in Adult AP which by early November was having a significant impact on her physical health.

9.2.2 Referring back to an earlier SAR report commissioned by South Tyneside for **Adult D** in 2016 one of the recommendations from that review was '*that South Tyneside Safeguarding Adults Board enhances the self-neglect and hoarding toolkit. The use of the revised toolkit should be promoted and practitioner feedback on its use obtained to further refine and enhance the toolkit over time'.* **[Recommendation 1]**

9.2.3 The self-neglect toolkit which if staff across all agencies had applied the information they had about Adult AP to would have evidenced that Adult AP met the criteria for 'person to be referred for section 42 enquiry' on the self-neglect screening tool, and 'high risk' on the risk threshold tool. This would have instigated earlier multi-agency coordination of risk meetings and the development of a shared risk assessment/care plan evidencing each agencies actions as well as the response to these from Adult AP and whether there were questions about her capacity to make these decisions. **[Recommendation 1]**

9.2.4 The STSCAP's policy and procedure in relation to self-neglect is clear and sets out what self-neglect is, what the aims and objectives are, considerations around mental capacity, information sharing and the criteria for referral to Self-Neglect Multi-Agency Complex Panel Meetings. The STSCAP have published a 7-minute briefing on self-neglect and trauma which post-dates the care of Adult AP, but which is another way of highlighting self-neglect and trauma to partner agencies and should be circulated again. **[Recommendation 1]**

9.2.5 Under mental capacity it states "When a person's self-neglect poses a serious risk to their health and safety, intervention will be required. Prior presumption of mental capacity may be revisited in self-neglect cases. There may be cause for concern if a person repeatedly makes unwise decisions that put them at risk of harm or exploitation. Or makes a decision that is obviously irrational or out of character."

9.2.6 In the care of Adult AP intervention was made but not until she had suffered significant pressure ulcers which had become infected in part due to the lack of personal hygiene.

9.2.7 The STSCAP may wish to consider whether safeguarding procedures had been instigated and the reasons for this discussed with Adult AP herself in 2020 she may have been engaged enough to submit her views on proposed actions, she appears to have been an intelligent woman who was not unwilling to share her opinions on her care and treatment.

9.2.8 The procedure for requesting case closure within ASC is overseen by a team manager or an assistant team manager; someone with supervisory skills and experience over and above that of the SW. Whether enough information was shared about the background to case closure requests is something ASC may wish to review considering the report.

9.3 <u>Legal Literacy</u>

9.3.1 From the information reviewed staff were aware of the Care Act (2014) and self-neglect as a category of abuse, however self-neglect in an adult who appears to have mental capacity to understand the risks of self-neglect and be able to decide to refuse support remains a challenge for staff. The current Mental Capacity Code of Practice does not cover this in detail. Executive function is often referred to in such cases and the importance of reassessing capacity when repeat refusals of support are rejected. Practitioners at the learning event agreed that executive function was something that some staff struggle with.

9.3.2 It is also evident that staff had knowledge and reasonable understanding of the MCA (2005) and its 5 principles[12] as well as an understanding of best interest decision making. British law clearly gives competent people the right to refuse any treatment. There was only one documented mental capacity assessment on Adult AP by the GP on 25th of November. The DN records demonstrate that capacity was considered and recorded in electronic records: 10.11.21, 18.11.22 (recorded at 15:01 and 15:03), 19.11.21 (recorded 16:13pm), 20.11.22 (recorded at 12 noon), 22.11.21 (recorded at 10:15am and 10:30), 23.11.22 (recorded at 11:30am) and 24.11.22 (recorded at 14:00). Other agencies appear to have been concluded this cognitively rather than committing repeated evidence of this to paper records.

9.3.3 The MCA (2005)[13] sets out that to be able to demonstrate a capacitous decision the person must; understand the facts involved in the decision, know the main choices that exist, weigh up the consequences of the choices and understand how the consequences affect them. Without recording the assessment process, it is harder to conclude that Adult AP could fulfil all 4 requirements. Empowering staff from all agencies to document mental capacity assessments particularly where there is repeated refusals of support to build up a more holistic picture of the persons presentation. **[Recommendation 3]**

9.3.4 There were several occasions when the DN considered and recorded mental capacity assessments on Adult AP, and when they attended with the GP on joint visits to Adult AP. On the referral to the DN service by the GP in November 2021 a request was made for a mental capacity assessment. This was referred back to the GP by the DN service as it was felt that at that time the GP was the most appropriate decision maker.

9.3.5 For those agencies that did consider whether the Mental Health Act (1983)[14] could have been used to assess Adult AP's mental health appropriate guidance was provided by

[12] Mental Capacity Act 2005 5 principles; presumption of capacity, being supported to make a decision, unwise decisions, best interests and least restrictive option.
[13] Mental Capacity Act (2005) 4 questions a person being assessed needs to demonstrate
[14] Mental Health Act (1983) is the main piece of legislation that covers the assessment, treatment and rights of people with a mental health disorder

MH colleagues. Adult AP's overriding problem was the significant issues with her physical health that needed managing first.

9.3.6 No agency considered seeking legal advice over the management of Adult AP when the risks to her health were escalating rapidly throughout November 2021. It is the Independent Author's view based on current case law that legal advice would have been that unless it could be demonstrated that Adult AP was having undue control and duress applied to her decision making by another person/persons then the Court of Protection would be unlikely to give a judgement forcing Adult AP to be admitted to hospital earlier for treatment. Therefore, no application to the Court of Protection could have been made.

9.3.7 The STSCAP may wish to review guidance for staff across the partnership in relation to seeking legal advice when they are managing cases of self-neglect, the person appears to have mental capacity to make an informed decision to refuse care and significant risks to their health and wellbeing are increasing. **[Recommendation 2]**

9.4 Information Sharing and Coordination of Care

9.4.1 There are multiple examples of information sharing and some coordination in the care of Adult AP throughout the timeframe of this SAR Overview Report, the MDT meeting held on the 17th of November being an example. It can be seen however that there were some gaps in information sharing, and key information wasn't always shared with the agencies who needed to know in a timely manner. The planned development of an MARM policy and procedure would support this finding. **[Recommendation 5]**

9.4.2 Taking the responsibility for the overall coordination of the care of Adult AP was picked up by no agency. The lack of guidance on how cases such as these were there is self-neglect and the person is deemed to have capacity to make 'unwise' decisions are the cases that nationally are recognised as being the most challenging for professionals, not least because there is no third party 'perpetrator' of the 'abuse'.

9.4.3 The commissioning process by the Local Authority in appointing North Haven Care Services to provide support to Adult AP was in accordance with their current contractual agreements. Following the SAR review for Adult AP the STSCAP may wish to seek assurance that communication pathways are clear between ASC and the care provider and who is responsible for contacting other external agencies when these are required to support high risk service users. Another of the recommendations from the SAR for Adult D was that *'South Tyneside Adults Board obtains assurance that South Tyneside Councils arrangements for commissioning and monitoring care and support for higher risk service users is effective'.* The STSCAP is advised to revisit this point and earlier recommendation. **[Recommendation 6]**

9.4.4 The SW could have agreed the safeguarding procedures on the 12th of November when the staff from NHCS alerted them to the deteriorating condition of Adult AP and her ongoing refusal of care rather than pausing them to gather even more information. [**Recommendation 7**]

9.4.5 DN's could have made a safeguarding referral on the 15th of November following receipt of photographs e-mailed to them by the daughter of AP which they noted to be worse than originally thought and did not appear to be new. The DN team would want to assess Adult AP and take their own photographs as per DN process. When this was completed, a referral was made. It was clear at this time that Adult AP was not moving sufficiently and had no access to adequate pressure relieving equipment, without immediate intervention the pressure ulcer would only get worse.

9.4.6 The mental capacity assessment of Adult AP was undertaken and documented by the GP on the 25th of November the date of Adult AP's admission to hospital which concluded that at that point she lacked the insight to understand the impact her decisions were having on her physical health. She was admitted to hospital following the agreement of professionals in attendance that she required a full assessment of her health. Adult AP and her family did not agree with this decision and the family feel Adult AP had grown tired of having to repeatedly express her views giving in and accepting that she was going to be admitted because an ambulance had been called.

9.4.7 The family also feel that some of the professionals at Adult AP's home that day were expressing views that their mother "was going to die in a few days". If this was the case then they believe that the EHCP should have been considered in greater depth which would have aligned with their mothers, and their view that she should not be admitted to hospital but remain and home and be kept 'comfortable and pain free' in her final days.

9.5 Trauma informed practice

9.5.1 There have been several training sessions held for staff on trauma informed practice in recent years. In some of the partnership agencies ACE's are covered in general safeguarding training. It is worth noting that although this SAR report centres around an adult her 'trauma' occurred when she was a child. It is not uncommon for trauma in childhood to continue to have effects into adulthood. The STSCAP may wish to consider making trauma informed training across agencies events that include both children's and adult professionals and carers. [**Recommendation 4**]

10. Recommendations

The recommendations have taken account of the changes to practice that the panel members identified from their own organisations.

Recommendation 1: The STSCAP should review whether the recommendation made following the SAR for Adult D has been met in respect of revising the self-neglect toolkit promoting it and obtaining practitioner feedback on it and if not what further remedial action is required.
Recommendation 2: The STSCAP should consider holding a working group made up of partner agencies senior practitioners to review the partnership boards policies and procedures in relation to self-neglect in those individuals that appear to have the mental capacity to refuse treatment. The groups remit would be to establish whether any further guidance or escalation

pathways would be helpful in the management of such cases including seeking legal advice.
Recommendation 3: The STSCAP should consider commissioning an audit of self-neglect cases to establish whether mental capacity assessments are being recorded where necessary and to identify whether these are documented to an acceptable standard. Where deficits are found these should be reported to the relevant agencies for remedial actions.
Recommendation 4: The STSCAP should consider hosting a 'learning from safeguarding reviews – trauma informed practice' online event to share the learning from reviews the board has commissioned in both children's and adults' services to where past trauma has played a significant part in the persons engagement.
Recommendation 5: Where the threshold for safeguarding is felt not to be met the STSCAP should support the planned development of the MARM process across the partnership which will provide assurance that multi-agency meetings are structured to improve co-ordination, continuity, and communication between services. It should be agreed which practitioner within each agency would have the lead co-ordinating role to oversee the MARM process for their organisation.
Recommendation 6: The STSCAP seek assurance that communication pathways are clear between ASC and care providers in relation to who is responsible for contacting other external agencies when their involvement is required to support high risk service users. Additionally, the STSCAP obtains assurance that South Tyneside Councils arrangements for commissioning and monitoring care and support for higher risk service users is effective.
Recommendation 7: The STSCAP members should reflect on the importance of their workplaces being environments that allow for adequate workforce development for example, escalation routes, safeguarding supervision provision and performance monitoring.

11. Glossary of Terms

AICT Acute Intermediate Care Team

ASC Adult Social Care

CCG Clinical Commissioning Group

DN District Nurse

DVT Deep vein thrombosis is a blood clot in a vein usually a leg

EHCP Emergency Health Care Plan

GP General Practitioner

MCA Mental Capacity Act

MHA Mental Health Act

NEAS Northeast Ambulance Service

NHCS North Haven Care Services LTD

OT Occupational Therapist

PLT Psychiatric Liaison Team

SAR Safeguarding Adult Review

STSCAP South Tyneside Safeguarding Children and Adults Partnership

STSFT South Tyneside and Sunderland NHS Foundation Trust

SW Social Worker

TVN Tissue Viability Nurse

Appendix 1

12. Chronology of key events leading up to hospital admission

Date	Agency	Summary of Key Events
12.03.2020	GP	Telephone contact with Adult AP to discuss x-ray results from the 4th March. They showed advanced degenerative changes, early wear and tear osteoarthritis at the knee and more advanced changes at the hip, but not sufficient to warrant hip surgery. Adult AP was seen by 2 physiotherapists at home who agreed with AP that as her pain level was so high there was little they could do to help until her pain was managed more effectively. Adult AP asked her GP if there was anything more effective she could take other than Codeine. She was advised that Paracetamol could be taken with an increase in Codeine dose, but that pain medication is only effective 25% of the time. Adult AP was advised that moving was the best thing to do. Written information was sent to her about the Escape Pain Programme in addition to providing the telephone contact number, she was also signposted to a website for pain management. The GP also advised her to contact ASC for support with toileting and personal care.
01.04.2020	GP	Telephone contact with GP by daughter of Adult AP to inform them that Social Services had advised that they could not provide support and that her pain needs to be managed to allow her greater mobility. GP documented Adult AP's fear of doctors and hospitals. The GP noted that poor mobility has been a chronic problem for the last 2 years. She is restricted to a chair in her sitting room and cannot get to the bathroom, family support with a wash whilst she sits in her chair and emptying a bowl used for toileting at the side of her chair. Adult AP was spoken to by the GP on this call, she stated she had increased her dose of Codeine and was taking Paracetamol. She reported that the Codeine was making her drowsy but not constipated, she asked for stronger analgesia. GP noted the difficult situation, unable to offer trail of steroid injections. Oromorph added to prescription to take before physiotherapist visits/attempts to transfer. The GP also added topical non-steroidal anti-inflammatory. Adult AP and her daughter were

		advised to contact Social Services again for support with toileting and personal care.
03.06.2020	GP	Daughter-in-law contacted the GP on behalf of Adult AP to report her legs were very swollen, she was spending all day in a chair and being moved to a recliner chair for sleep overnight. Telephone call with Daughter-in Law to report poor living conditions following conversation with daughter-in-law. Adult AP reported to the GP that she was feeling alright apart from the chronic pain and was taking her medication as prescribed. Family was supporting her with meals, her appetite was good, no apparent weight loss reported. Not able to wash properly or change clothes often.
03.06.2020	ASC	Contacted by family of Adult AP to request urgent needs assessment as advised by her GP.
05.06.2020	ASC	Initial telephone call from Occupational Therapist (OT), Adult AP agreed to engage with physiotherapy. The Acute Intermediate Care Team (AICT) advised the OT it would be 3 weeks before she would be seen. OT offered equipment in the interim such as a commode and stand aid which Adult AP declined acknowledging the risk of her skin breaking down, she stated she was willing to wait for physiotherapy input.
08.06.2020	STSFT	The DN's sought consent from Adult AP to undertake a referral for a needs assessment by ASC. Adult AP consented to this but stated she would refuse everything offered to her. At this visit Adult AP's daughter informed staff that her mother was 'angry' that the AICT had been referred to without her consent. Adult AP felt she was coping and did not require input from ASC.
01.07.2020	STSFT	Telephone call to Social Worker (SW) from physiotherapist who advised they were closing their involvement as Adult AP did not have any therapy needs.
03.07.2020	GP	Following receipt of a letter from the OT on the 1st July a telephone review took place and AP agreed to medication for muscle spasms.
03.07.2020	STSFT	Conversation with SW. The SW had advised the OT that Adult AP had declined a care package as she felt her family could meet her needs. Adult AP had indicated her reluctance to move any furniture from the sitting room to allow moving and handling equipment and had refused to have a bed downstairs.
06.07.2020	ASC	Telephone contact between SW and Adult AP, outcome recorded that she refused any formal carer support. It was

		noted that family and District Nurse (DN) continue to provide support SW requested case closure.
09.07.2020	ASC	Family contact SW to inform them that AP was now accepting of equipment.
27.07.2020	STSFT	Adult AP's daughter stated that she felt her mother would require a care package in the future. The AICT staff provided Adult AP's daughter with the contact details for the 'Let's Talk' team to discuss this further with ASC.
August 2020	STSFT	In August 2020 the possibility of having a hospital bed was discussed with Adult AP. DN's encouraged Adult AP to think about this and the conversation was revisited in a further visit the following month. Adult AP declined on both occasions stating that to have this equipment in her sitting room would feel to her like she was 'giving up'. The same month AICT staff documented at that point in time there was no further need for therapy. Adult AP was comfortable and safe transferring with the stand aid hoist with daughter's support. Adult AP had a wheelchair and ramp which allowed access in and out of the property. The home was described as no longer smelling of urine and Adult AP 'seemed much happier in herself'.
24.08.2020	ASC	STSFT staff contact SW and requested a further OT assessment.
01.09.2020	ASC	OT assessment identified equipment and further adaptations.
21.09.2020	ASC	Following further telephone assessment by SW home care support for Adult AP was agreed as being required 3 times a day.
22.09.2020	STSFT	New pressure damage to the backs of the tops of AP's legs reported to community staff by the daughter of AP, DN input requested.
22.09.2020	STSFT	DN home visit to AP who was unable to weight bear and would not allow the DN's to use the stand aid. Daughter attended to assist, and consent was obtained to assess the backs of legs. Skin intact but discoloured, evidence of barrier cream application noted. AP was sitting on a wet incontinence sheet on top of a disposal continence sheet, she declined continence assessment. Further referral to OT declined by AP, discussion followed about pressure relieving mattress and profiling bed to assist in relieving constant pressure on bottom. AP expressed the view that if she accepted these she would be 'giving up'.

		Benefits of equipment discussed with AP and daughter, written information about pressure ulcers given to AP and daughter. DN's advised that if she changed her mind she could contact their service, telephone number given. AP was then closed to DN input.
28.09.2020	ASC	Home care to commence. OT initial assessment for adaptations ordered.
06.10.2020	ASC	SW telephoned Adult AP to discuss the care package, AP raised no concerns, SW requested case closure.
12.10.2020	GP	Adult AP telephoned her GP to request medication review as she had been informed that this would be required before her repeat prescription ran out. Adult AP was asked about her medication and if she was taking as prescribed, she stated she was but only took the morphine some nights to help her sleep. She confirmed that she had carers to help a couple of times a day and family were also supporting her.
12.04.2021	ASC	Adult AP telephoned SW to request that the teatime carer call was dropped as her family were supporting her. Case closed the following day.
08.09.2021	ASC	Telephone contact from Adult AP's daughter to SW to request an increase in care support, this was agreed the following day.
10.09.2021	ASC	Confirmed package of care to commence on 13.09.2020.
28.09.2021	ASC	SW completed a home visit and identified support 3 times a day with family support was meeting Adult AP's needs at this time.
21.10.2021	ASC	A face-to-face needs review was undertaken, no changes to package required.
02.11.2021	NHCS	Team Leader spoke with the daughter of Adult AP regarding her carers concerns with Adult AP's engagement with meeting her support needs. Daughter confirmed the GP had been contacted to assess and review pain management. Daughter contacted SW to request that the family's concerns and those of NHCS carers were escalated regarding Adult AP's non- compliance of care, acceptance of fluids, nutrition, and her deteriorating health.
05.11.2021	NHCS	Initial concerns raised with NH Care Manager at the office about Adult AP starting to refuse personal care and support with nutrition on some visits.

9.11.2021	GP	Home visit to Adult AP seen with daughters present. Discussed how AP had been recently, her main concern was with the chronic pain in her legs making movement very painful. Daughters reported that AP was resistant to physiotherapy because she found it too painful. Since being confined to a chair Adult AP has gradually developed fixed flexion deformities of her neck, left foot and hand. She had lost weight over the past few months, as a result the stand aid sling was too big and neither daughter or carers felt able to use it. AP was noted to be doubly incontinent and not able to manage hygiene needs. GP discussed with Adult AP the option of admission to 24-hour care placement, but she would not consider this at all. Again, she expressed her phobia of hospitals and stated she found the GP visiting very hard, but she was aware she needed help. Adult AP stated she had not eaten for 7 days now and was only sipping water because she felt sick and was worried this might cause diarrhoea, she denied abdominal pain. AP's Daughter reported an open pressure area on buttock, the GP was not able to see this because they could not move her. Adult AP stated she had accepted how she was and was not suicidal. Daughter stated her had expressed a wish not to be here and her concern was that her mother was starving herself. The GP discussed with Adult AP and her daughter the limitations of what they could do without a thorough examination, blood tests and investigations. Discussing Adult AP's apparent low mood, she accepted that she was low in mood but felt this was due to pain and nausea and refused further medication or input at this time. Following further discussion, she agreed to try a longer acting analgesia and antiemetic for nausea to see if it boosted her appetite. She was referred to DN for pressure ulcer care but declined further physiotherapy input. The GP agreed to call back following week to see how she was getting on with the new medication regime.
09.11.2021	ASC	Contacted by daughter of AP to request OT assessment as moving and handling assessment needed review following AP's weight loss. New sling was provided the following day and a call was made to see if it was proving effective.
10.11.2021	STSFT	Home visit to AP by DN's to assess pressure ulcer and continence status. Assessment declined by Adult AP until new pain medication obtained from GP, daughter collecting today. Daughter felt her mother had the mental capacity to make this

		decision. The DN requested that the daughter discussed the detrimental effects of immobility and poor hygiene with Adult AP.
11.11.2021	NHCS	Care staff reported to their office that Adult AP has refused personal care, fluids and food.
11.11.2021	STSFT	DN's visit again to attempt pressure area assessment care staff present, report category 2 pressure damage to left buttock, Adult AP declined to be hoisted as stated that she was nauseous and in too much pain. DN's agreed to attend when carers present to support access to AP's pressure areas. Adult AP was again advised of the risks of not having a full assessment. Adult AP was felt to understand the risk and still declined. Daughter was advised to apply barrier cream to mother's skin when she was cleaned, AP's daughter stated she would attempt to photograph the pressure damage and send these to the DN's.
12.11.2021	GP	SW contacted GP regarding concerns over Adult AP's non-engagement. Daughter and carers concerned as her mother was not responsive to medication and wasn't eating or drinking. SW spoke to the daughter who stated that Adult AP was still not eating very well and had ongoing diarrhoea. The outcome was to try Imodium and encourage fluid intake. For telephone review on Monday.
12.11.2021	ASC	OT contacted the family to check everything was ok, advised that their mother was still refusing profiling bed and pressure relieving mattress. SW contacted the care provider due to concerns that Adult AP had disengaged with personal care. SW advised the care provider to continue to monitor and that DN had confirmed their attendance. Daughter of Adult AP advised to call 111/999 if Adult AP required medical intervention. Care provider updated.
12.11.2021	NHCS	SW was contacted the Registered Manager at NHCS to inform of possible safeguarding notification in relation to concerns about self-neglect, increasing refusal of care and degrading of skin. The SW was asked for advice in relation to the safeguarding notification and confirmed she would visit AP and the family and to 'hold off' the submission of a safeguarding notification.
15.11.2021	GP	Telephone call with daughter and Adult AP for an update. Adult AP felt the medication was not working, she hadn't started Imodium and hadn't been taking Oramorph in addition as too

		groggy on the long-acting morphine, would rather go back to Codeine. Agreed trial of Amitriptyline to be taken at night. Left leg was reported to be very swollen, not painful but very uncomfortable. Leg was not hot or red, no chest pain or breathing problems. Declined blood tests or admission for ultrasound for possible DVT. DN couldn't lift AP during visit, but daughter advised that she had photographs of the pressure ulcers. Family concerned about how rapidly the sore was growing and asked for more urgent DN visit. Had OT coming tomorrow to discuss adjustable bed.
15.11.2021	STSFT	DN's documented pressure damage was unstageable as not yet seen by staff. Photographs of pressure damage sent by family to DN e-mail address. Pressure damage appeared worse than originally thought and was not new. Discussion with Adult AP's daughter that she would be better being nursed in bed for pressure relief and regular position changes, daughter advised that her mother had agreed to this, and the OT was visiting tomorrow.
16.11.2021	STSFT	DN joint visit with OT, Adult AP declined to be moved. Not able again to view pressure ulcers, bed mattress and slide sheet on urgent delivery.
17.11.2021	NHCS	Home Care Manager rang the SW to see if there was any update on the concerns raised with her on the 12th. The SW said she would chase it up today and ring back with an update.
17.11.2021	GP	Call from paramedic as Adult AP had slipped out of her chair, assisted back to chair but refused transfer to hospital. Ambulance staff were called by carers who had found her in this position when they attended the morning call. Paramedic concerned regarding pressure ulcers and incontinence. They were advised that DN's were involved, and bed and mattress were on order. Called by OT who felt that AP needed admission to hospital, but AP was refusing. No reason to doubt mental capacity as she had agreed to transfer to a bed and there was a plan to manage the long-term issues.
17.11.2021	ASC	Multi-Disciplinary Team (MDT) meeting - SW spoke with Adult AP's daughter who advised that she had sent DN's photographs of pressure ulcers due to growing concerns. SW spoke to care provider and OT regarding concerns and was advised that DN was attending the following day.

17.11.2021	NHCS	Home Care Manager rang SW to see if there was any update on the concerns raised with her on the 12th. SW stated she had been off work but would chase it up today. SW was advised that the situation was escalating, SW stated she would ring back later with updated information.
18.11.2021	GP	Seen at home with daughter, OT and DN present. Daughter informed professionals that she had identified the pressure ulcers on the 6th of November. Awaiting transfer to hospital bed. Adult AP stated she felt well other than a sore hip from yesterday. Discussed the concerns professionals had that she was sitting in the chair for too long in faeces and urine. They also explained the decline in her physical health and that taking some bloods for analysis would help. Adult AP reiterated her fear of hospitals and doctors and expressed that she had only ever been in hospital 3 times in her life, twice as a small child with scarlet fever and the 3rd occasion for the birth of her son which left her crying for days on her return home. Adult AP understood that there was a real risk of further deterioration in her health, including severe infection, clot in her legs and death. She stated that her fear of hospitals and needles was greater, and if this meant her demise then so be it. Based on this conversation the GP felt AP had capacity to make this decision. She did agree to a trial of morphine liquid before the bed transfer later that day. Daughter also requested other medication in liquid form because Adult AP was vomiting back tablets. GP discussed the meeting with SW at ASC's request, informed the SW of the situation and AP's ongoing refusal of medical treatment. SW visited AP with the OT, OT Manager as well as a Safeguarding Manager from ASC.
18.11.2021	ASC	DN contacted team in huddle, advising GP and DN involvement required alongside risk assessments. DN telephoned ASC in relation to Adult AP's self-neglect, refusing hospital admission and states that Adult AP had the mental capacity to make this decision.
18.11.2021	NHCS	Registered Manager contacted by DN regarding concerned in relation to skin integrity and safeguarding. The Registered Manager explained that they had raised their own concerns with the SW and daughter on 12th of November.
18.11.2021	STSFT	Home visit by DN, strong odour in Adult AP's home, possibly from pressure ulcer as well and incontinence. Daughter stated

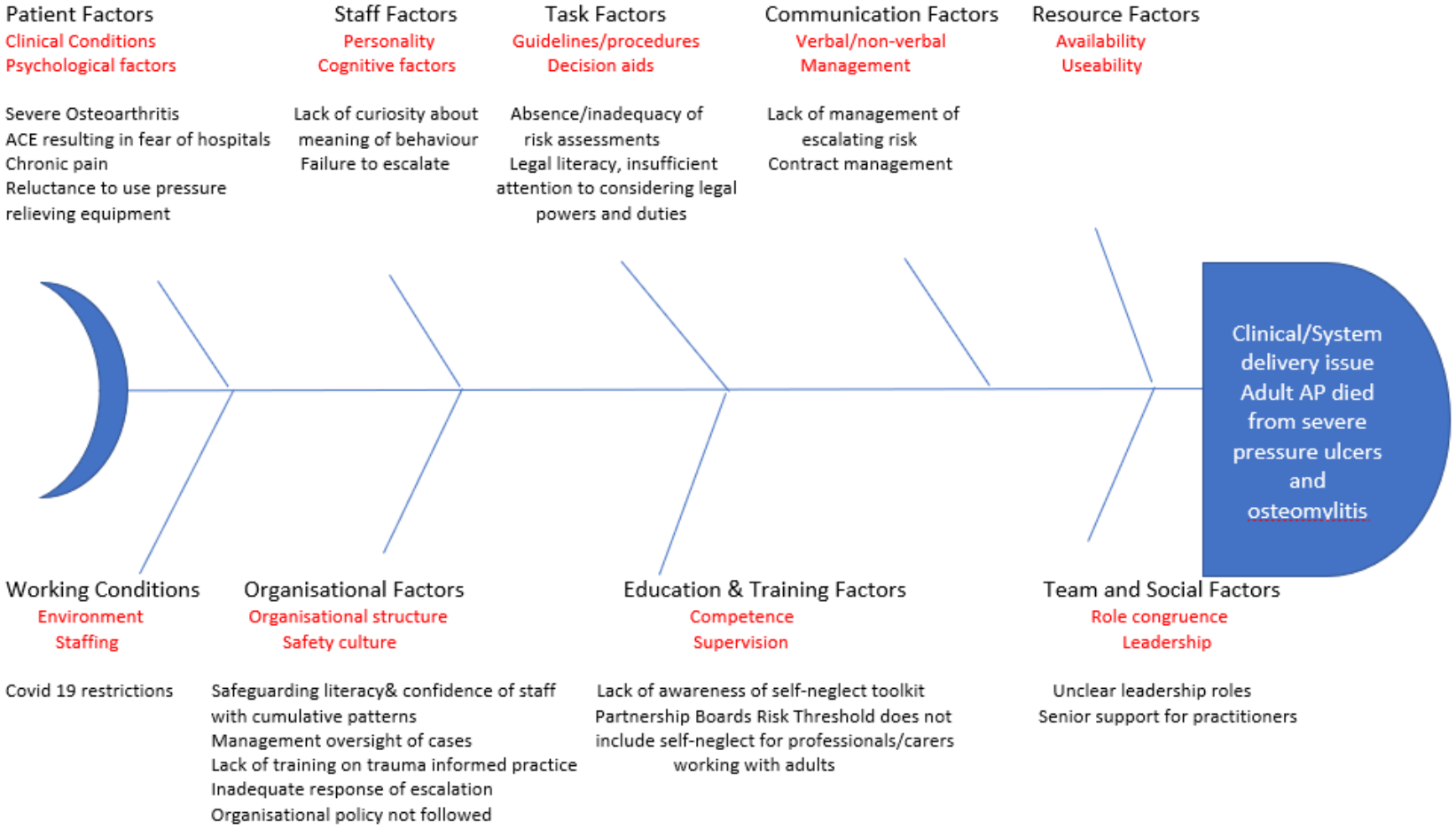
		that AP had not had her pad changed or been moved for 4 days, and that she had identified the pressure ulcer on the 6th of November. Daughter informed DN that until approximately 10 days ago AP was able to use the stand hoist but is now unable to due to pain in legs. Photographs of wounds were taken with Adult AP's consent. A pressure ulcer leaflet was given to the daughter with advice to read and adhere to advice given. A safeguarding referral was discussed with Adult AP and her daughter to gain consent. DN contacted the SW to advise they would be submitting a safeguarding referral for self-neglect, following discussion with their Trust safeguarding team. The Trust safeguarding staff spoke with the LA safeguarding manager who stated they were already aware of the concerns. The DN raised her concerns in relation to the duration over which the pressure damage had occurred and that the DN team had not been notified of the situation earlier. The CCG safeguarding staff were also made aware of the concerns. On transfer of Adult AP to the hospital bed the extent of the pressure ulcer was assessed and found to be severe. Urgent MDT arranged for the following day for all professionals involved. Referral to dietician and Tissue Viability made.
19.11.2021	GP	Request for EHCP re home care palliation at home in the event of decline rather than hospital admission. Medical input shared at MDT/safeguarding meeting. Prescription given for topical creams as DN requested.
19.11.2021	ASC	MDT/safeguarding meeting with OT, GP, Carers and Daughter present. ASC safeguarding team informed of the situation. Daily DN visits to commence.
20.11.2021	STSFT	DN home visit, Adult AP expressed extreme pain when moving into position for dressing change, wound appeared to be mostly necrotic tissue.
21.11.2021	STSFT	DN home visit, wound malodorous and appeared to have deteriorated from the previous day.
22.11.2021	STSFT	DN home visit, wound redressed and assessed as being systemically high risk of infection, TVN accepted referral. Adult AP required a higher-grade mattress, discussed with OT.
23.11.2021	STSFT	DN home visit, wound redressed higher-grade mattress arriving on 25th of November.

23.11.2021	ASC	Joint home visit by SW with Operational Manager who felt that Adult AP had the mental capacity to make decisions about her care and support.
24.11.2021	ASC	OT reports that carers are concerned that nursing input is required. 2nd Risk Management meeting arranged for 26th.
24.11.2021	STSFT	Tissue Viability/DN home visit. Adult AP declined urinary catheter insertion. Extent and severity of pressure ulcer documented deep wound category 4. Noted extensive moisture associated with skin damage due to incontinence. AP declined to have bloods taken and hospital admission, only able to treat conservatively at home. Adult AP advised staff that the carers had not been washing her or applying barrier cream. She also stated that she had no diet for 4 weeks and was only taking fluids. Attempt to update SW via telephone unsuccessful. Daughter-in-law made aware of what Adult AP had stated and agreed to inform Adult AP's daughters. DN's contacted the care provider and were told that AP was refusing this care when their staff were offering it.
25.11.2021	STSFT	DN requested GP home visit to Adult AP due to increased concerns over refusal of treatment. Adult AP had discussed with them her 'traumatic childhood hospital admission', the DN advised the GP that they felt this was having a significant impact on her choices in relation to medical treatment and hospital admission. NHCS staff were contacted and informed DN that Adult AP was refusing care and support. DN spoke to SW about her concerns that carers were not making enough effort to engage with Adult AP and were allowing her to decline treatment too easily. SW agreed to pick this up with the care provider. During the MDT AP stated that she did not wish under any circumstances to be admitted to hospital, AP's family advised that AP wished to remain at home regardless of the consequences.
25.11.2021	GP	Home visit to AP with OT, DN, HC and Carer following DN sharing their concerns from yesterday's visit. Spoke with SW on the telephone discussed the need to constantly reassess mental capacity and ability to admit to hospital. Spoke with psychiatrist, discussed Adult AP, her long standing fear of hospitals and refusal to have blood tests as well as the possibility that delirium was clouding her ability to make informed decisions. The Psychiatrist advised that Adult AP could not be assessed under the Mental Health Act because she was clearly physically unwell. It was more appropriate to use

		the Mental Capacity Act and best interest decision if found to lack capacity. Following a long discussion with Adult AP the GP informed her that in her opinion she needed hospital admission, or she would die at home. She was also advised that not eating would only make the situation worse. Adult AP again spoke about her fear of hospital, she again refused blood tests and catheterisation to improve the management of her incontinence. The GP explained that in hospital they could support her with wound care, nutrition and pain. They also discussed dying at home and resuscitation. Adult AP stated she would like to be resuscitated for her family's sake and she recognised that she may have no choice. The GP discussed that they could do a EHCP stating 'keep offering admission,' and that they could look at alternative analgesia e.g. patch and consider palliative anticipatory medication but they would need to discuss concerns over mental capacity with the team as her past experience of hospital seems to be having a great impact on her current situation. The GP completed mental capacity assessment form concluding that AP lacked the insight into the severity of her illness, and she could not be properly assessed in the community. Adult AP's family made aware of the best interest decision and were informed that an ambulance had been requested to transfer their mother to hospital.
25.11.2021	ASC	Call requested home visit to Adult AP due to ongoing concerns around refusal of medical treatment. SW confirmed the ECHP was in place.
25.11.2021	NEAS	Ambulance called to transfer Adult AP to hospital due to significant self-neglect and severe pressure ulcer with risk of infection.
25.11.2021	STSFT	AP admitted to hospital following safeguarding referral by DN service for self-neglect.
26.11.2021	STSFT	Adult AP's daughter advised staff that their mother had a 'degree of post-traumatic stress disorder (PTSD) in relation to hospitals which resulted from a prolonged period of hospitalisation as a child.

26.11.2021	CNTWFT	Referral to the Psychiatric Liaison Team received, it was felt that due to the severity of AP's physical health as assessment would not be appropriate.
28.11.2021	STSFT	Adult AP died in hospital from sepsis, she had not responded to treatment given, and was subsequently kept comfortable on a morphine infusion when it was agreed that further treatment was not in her best interest.

Adapted from the National Patient Safety Agency Analysis Toolkit **Appendix 2**



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14. Statement by the Independent Reviewer

The reviewer, Michelle Grant is independent of the case and of South Tyneside Safeguarding Childrens and Adults Partnership and its partner agencies.

Prior to my involvement with this Safeguarding Adult Review:

I have not been directly concerned with the adult or the carers and professionals involved with the adult, nor have I given any professionals advice on this case at any time.

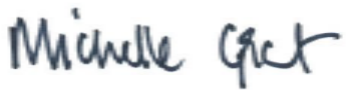
I have no immediate line management responsibilities for the practitioners involved.

I have appropriate recognised qualifications, knowledge, experience, and training to undertake this review.

The review has been conducted appropriately and with rigorous analysis and evaluation of the issues set out in the Terms of Reference.

Independent Reviewer

Signature:



Name: Michelle Grant

Date: 30.12.2022