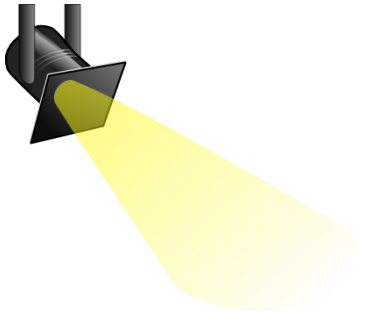
Swindon Safeguarding & Community Safety Partnership



Spotlight on Self-Neglect

22nd March 2023

Overview of the session

0930	Welcome and Housekeeping	Jackie Barstow, Learning & Development Manager, Swindon Safeguarding Partnership (SSP)
0935	Overview of the session	Helen Jones, Partnership Safeguarding Development Manager, SSP
0940	Feedback	Jackie Barstow/Helen Jones
0955	Learning from Safeguarding Adult Review's (SAR's)	Helen Jones
1010	Overview of the SSP Multi-Agency Self-neglect policy and guidance	Helen Jones
1030	Case study discussion 1	Kay Giblett, Environmental Health Officer, Housing & Environmental Protection, Swindon Borough Council
1050	Questions	
1100	Break	
1110	Overview of hoarding protocol	Helen Jones
1120	Case study discussion 2	Kati Wood, Live Well Swindon
1140	Questions	
1150	SSP Training and Resources	Jackie Barstow
1151	Evaluation and close	Helen Jones/Jackie Barstow

POLL

Learning from Safeguarding Adult Reviews

Helen Jones

Development Manager

Swindon Safeguarding Partnership

SAR Terry

Terry died on 1st June 2019 in hospital. Cause of death was given as liver cirrhosis accompanied by Hepatitis C. Terry was aged 71 and White British. His next of kin was recorded as his brother, with whom it appears that he had some contact. However, during the review it became clear that there were other relatives of whom services appear to have been unaware.

Terry lived in warden assisted accommodated and had two main associates who collected his weekly allowance from the Swindon Borough Council (SBC) Money Management Team (MMT) and bought his shopping – food, cigarettes and alcohol. This arrangement was longstanding. Terry's health history involved a stroke that had left him with left-sided weakness. SBC's first contact with Terry was in 2004 at which point his alcohol misuse was identified. This was to become one of the running themes through the involvement of services with Terry. Significantly, for what emerges as a pattern in this case, GP records contain references to concern about frequent falls, poor memory and alcohol abuse in July 2014, and to concerns about Terry not eating in July 2015. Concerns about Hepatitis C are recorded from 2015 onwards, due to previous intravenous drug use it is suggested.

Between May 2005 and the end of 2008, there were numerous on-going concerns regarding financial exploitation, non- payment of bills, alcohol dependency, self- neglect and memory difficulties. These concerns become running themes in the period on which this SAR mainly focuses. From the outset Terry's engagement with care and support appears to have been variable. A care package had commenced in January 2007 but this was cancelled in 2009 when Terry's main associates became, effectively, his informal carers.

The report noted that one aspect of Making Safeguarding Person and the evidence base for working with people who self-neglect is an understanding of the person's history and how life experiences are influencing and impacting on their present situation and behaviour. Very little such detail is recorded on the combined chronology or the SAR referral. It is questionable whether there was sufficient professional curiosity regarding the background to his alcohol abuse, rejection of formal care, and self-neglect. For example it is observed that Terry had a dislike of formal carers but it is unclear whether anyone tried to understand the origin of this dislike; in any event the outcome of any such a conversation was not recorded.

Key Findings

- Professional curiosity
- Making Safeguarding Personal –improved consistency.
- Missed opportunities for mental capacity assessment, executive capacity, and impulse control relating to substance misuse.
- Risk assessments were completed at different times the risk of financial abuse or exploitation was never fully resolved.
- Need for improved Supervision and management oversight.
- No lead agency leading to lack of escalation of concerns.
- 42(2) enquiry; there was significant delay in progressing the second to the formal enquiry stage.
- Standards of records and record-keeping.
- Role of informal carers – improved access to carers assessments.
- MMT Team – clear plans and annual reviews of service users' financial affairs.

Making Safeguarding Personal

Making Safeguarding Personal sits firmly within the Department of Health (DH) Care and Support Statutory Guidance, as revised in 2017 that supports implementation of the Care Act (2014). It means safeguarding adults:

• is person-led • is outcome-focused • engages the person and enhances involvement, choice and control • improves quality of life, wellbeing and safety (paragraph 14.15)

Making Safeguarding Personal must not simply be seen in the context of a formal safeguarding enquiry (Care Act, 2014, Section 42 enquiry2), but also in the whole spectrum of activity. It should focus on the person's wishes, feelings and desired outcomes. One aspect of Making Safeguarding Personal and the evidence base for working with people who self-neglect is an understanding of the person's history and how life experiences are influencing and impacting on their present situation and behaviour. It is important to demonstrate professional curiosity to understand the choices that an individual is making and what might be an underlying reason for refusal of care and support, for example. It is important to gain an understanding family dynamics and being aware of next of kin as well as those who may play an informal care and support role in the life of an individual.

Swindon Safeguarding Partnership

Learning Leaflet

Safeguarding Adult Review: Terry

November 2019

Multi Agency Working

The evidence base for best practice in working with adults highlights the importance of interagency communication and collaboration, coordinated by a lead agency and key worker who oversees this work. A comprehensive approach to information sharing is important to ensure each agency/service has a holistic view of what is happening with an individual.

It is recommended that multi-agency meetings are used to pool information as well as risk and mental capacity assessments, to agree a risk management plan and to consider legal options.

Terry died in hospital in June 2019 aged 71 from liver cirrhosis accompanied by Hepatitis C.

Terry experienced self-neglect, financial exploitation and alcohol dependency in the years leading up to his death. In November 2019 a SAR was undertaken following Terry's death and key areas for learning were identified.

This learning leaflet sets out these key areas for learning. These areas have also been incorporated into the SSP strategic plan and the Learning and Development offer, the outcomes of which will be monitored to ensure they are consistent with the learning to improve frontline practice.

Mental Capacity Act and Mental Capacity

The Mental Capacity Act 2005 (MCA) is designed to protect and empower individuals aged 16 and over and help to safeguard the human rights of people who lack (or may lack) mental capacity to make decisions about their care and treatment.

Additional considerations need to be made when an individual may have fluctuating capacity in circumstances such as alcohol misuse, require assessment of their executive capacity and impulse control relating to substance misuse.

It is recommended within NICE guidance to include real world observation of a person's functioning and decision making and to adopt a longer term perspective on someone's capacity rather than assessing it in a single point in time. Especially where fluctuating capacity can be related to alcohol misuse.

Research in Practice brief guide access here

An easy read guide to the MCA can be accessed here

Risk Assessing and Risk Management

A model of good practice based on research and finding from previous SARs shows that comprehensive risk assessments of individuals are advised, especially in situations of service refusal. Mental capacity assessments should form part of a risk assessment, especially of executive functioning in cases where there is shown to be medical evidence of changes in the brain which would affect this functioning.

Risks including financial abuse and coercion related to this, self-neglect and risks associated with self neglect which could include a lack of food and other necessities for daily living , refusal to rake medication or accept support services should be considered as part of a risk assessment.

Professional curiosity and assessment are fundamental when concerns occur repeatedly and when a person's decision-making maintains or increases risks of significant harm.

Self Neglect

The term Self Neglect can cover a wide range of behaviours such as neglecting to care for one's personal hygiene, health or surroundings. it can also include behaviour such as hoarding.

The Adult Self Neglect and Hoarding Guidance can be downloaded from our website: https://safeguardingpartnership.swindon.gov.uk/downloads/file/394/adult_self_neglect_and_hoarding_guidance

The SSP provide an e-learning course on Self Neglect for anyone working with vulnerable adults to develop an understanding of self-neglect and the complex issues that can impact a persons ability to make decisions. This training will look at how to balance addressing the issue of self-neglect with an individual's right to private life and health and how to make safe decisions. Click https://www.virtual-college.co.uk/courses/safeguarding/self-neglect

SAR Kieran

Kieran died at his home in January 2019 aged 65 following a period of illness. Kieran was diagnosed with mild learning disabilities around the age of 18 and first had contact with mental health services following his father's death 3 years later. He experienced self – neglect, hoarding, mental illness and exploitation in the years leading up to his death.

Kieran's early history includes a record of mild learning disability in 1972 and a first contact with psychiatric services in 1975 following his father's death. His IQ was given as 63 and obsessive symptoms and ritualistic activity were recorded. His mother's death in 2002 prompted renewed contact with psychiatric services following an overdose. Appointeeship with respect to his financial affairs appears to have begun at this time. His weekly allowance was collected by a carer. His family believe that this had begun as a formal arrangement around 2005, facilitated by Swindon Borough Council (SBC). Records from that time are not available and it became widely accepted by agencies involved that it was a private arrangement.

The house in which Kieran lived was owned by his extended family and he was not charged rent. In the final few years of his life there were increasing concerns about self-neglect and hoarding. His case had been reopened by Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) by the beginning of 2017 and a care and support package had additionally been arranged from April 2018 to address Kieran's self-neglect and hoarding.
There were concerns that Kieran was at risk of exploitation. There were also concerns about the adequacy of support being provided by the private carer. His relatives have described Kieran as a shy man, reticent of strangers. Practitioners working with Kieran echo this description. Kieran could be reluctant to allow access into his home and expressed dislike of too many visits and visitors, practitioners and relatives alike.

Key Findings

- Professional curiosity.
- Making Safeguarding Personal –improved consistency.
- No care plan to address adult safeguarding concerns.
- Risk assessments, and risk management and contingency plans, were not up-to-date and were not revised after key episodes.
- Missed opportunities for Mental capacity assessment, executive capacity.
- Self Neglect & Hoarding.
-Role of informal carers – improved access to carers assessments.
- MMT Team – clear plans and annual reviews of service users' financial affairs
Need for improved Supervision and management oversight.

Learning Leaflet

Safeguarding Adult Review: Kieran, January 2019

Further learning

making sense of Mental Health problems
Personalisation
Safeguarding vulnerable adults – Level 3
Self Neglect
Understanding Mental Capacity

Exploitation

Who: A person who exploits a vulnerable adult may be a carer, friend or relative
How: They may exploit the person's money or assets
Signs: Person allocated to manage finances and affairs may be evasive, disparity between a person's finances and their living arrangements or a failure to provide receipts.

(Social Care Institute for Clinical Excellence, 2015)

Record Keeping

Good record-keeping is central to effective safeguarding. It is particularly important when you are assessing a person's capacity to make their own decisions. People benefit from records that promote good communication and high-quality care.

You should record decisions and actions that you decided not to take, as well as where an adult's finances are managed on their behalf. Records must be subject to robust and regular checks.

Learning from SAR Kieran

This learning leaflet sets out learning for professionals which has been identified from a SAR in respect of Kieron. The learning identified has been incorporated into the SSP Strategic plan and the evolution of the Learning and Development offer. The outcomes of which will be monitored to ensure they are consistent with the learning to improve frontline practice.

Kieran died at his home in January 2019 following a period of illness. Kieran was diagnosed with mild learning disabilities around the age of 18 and first had contact with mental health services following his father's death 3 years later. Kieron lived with his Mother until she passed away in 2002.

Kieran experienced self – neglect, hoarding, mental illness and exploitation in the years leading up to his death. Following Kieran's death a SAR was undertaken and key areas for learning were identified.

Mental Capacity Act and the Care Act

The MCA and the Care Act work together to promote the empowerment, safety and wellbeing of adults with care and support needs.

Both the MCA and Care Act promote independence and exercise as much control over their lives and any care and support they receive.

Any capacity assessment in relation to self-neglect or hoarding behaviour must be time specific and relate to a specific intervention or action. Best interest decisions should be taken formally with professionals involved and anyone with an interest in the person's welfare, such as members of the family (Preston-Shoot, Braye & Orr, 2014)

Worried about an adult?

Multi Agency Safeguarding Adults online referral form
Adult safeguarding team: 01793 463555
Email: adultsafeguarding@swindon.gov.uk (M-F, 8.30-5pm)

Non Engagement

Agencies that support vulnerable adults can often find it difficult to engage with those who choose not to accept advice or attend appointments.

Every attempt must be made to engage with the adult. This could be via home visits, telephone calls or via family.

If the adult is involved with other services make contact with them to explore the best way to engage the adult.

Hoarding

Hoarding is where someone possess a significant amount of clutter that becomes unmanageable.

Extreme hoarding meets the criteria for a Mental Capacity Assessment (Hardy, 2018)

Section 11 of the Care Act gives practitioners the legal authority to conduct an assessment where section 42 threshold is met but a person with capacity is refusing an assessment. In cases of self-neglect and hoarding, this is helpful for practitioners to remember as they can undertake an assessment even if this means obtaining information, without the person's input.

What did the SSP do following SARs Terry and Kieran?

- Established task and finish group to revise and improve the Policy and Guidance on Self Neglect, published July 2021
- New SSP multi-agency Self-Neglect training to launched from July 2021.
- Improve understanding of Care Act legislation – Legal literacy training offered in new SSP L&D Offer.
- Improvements on-going inter-agency communication, information sharing and joint decision making in safeguarding risk assessments.
- Work to embed the practice of Making Safeguarding Personal.
- Professional Curiosity - Resource pack for sharing learning and improving practice now available on SSP website.
- Money Management Team series of training has been completed including social work team, new referral form developed, desk-top review completed of any informal arrangements.

SAR Brenda

Brenda was aged 75 years when she died on 03/02/21 in hospital, after several weeks of accelerating deterioration at home. From Christmas Eve 2020, Brenda withdrew from essential activities of daily living. The first signs of this were neglect of the home environment with rotting food and milk and a build-up of unwashed dishes. By 14/1/21, the visiting community nurses were concerned about poor food and possibly poor fluid intake. Conditions were exacerbated by the results of unmanaged incontinence of faeces, visible about the home and on clothes, on the bed and on Brenda.
Brenda lived alone, did not go out, and wanted to avoid Covid 19 exposure. Brenda was estranged from her son, for reasons that were not explored at the time. In the past he had arranged food deliveries for her but there was otherwise not a known history of family involvement with Brenda. On 2/2/21 when Brenda was extremely ill and being taken to hospital, her son could not be notified since there was no current telephone number on record.

There was little known about her life. Brenda had multiple health needs (heart disease, kidney disease, Sjogren's syndrome, anaemia), Depression and experienced Self-neglect. Brenda had contact with services leading up to her death including Community nurses visited weekly to give an Eprex injection, Advanced Clinical Practitioner from GP surgery, GP, Adult Safeguarding Team and Initial Contact Team at Swindon Borough Council.

The report noted that **Self-Neglect procedures were not referred to.** Brenda was identified as self-neglecting, with no reference to the self-neglect policy and procedure hence there was no interagency or best practice framework to inform work with Brenda and between services. Prior to this review, the need to embed training in practice was recognised as a priority and a staff survey was undertaken on the obstacles to working with people who self-neglect. The outcome of this will be used to inform future policy and procedural revisions.

Key Findings

- Safeguarding responses
- Care Act assessment and ASC response
- EW's physical health needs
- Inter-agency communication and collaboration
- Risk assessment
- Person-centred approaches
- Contact with family
- Use of advocacy
- Recognition and response to self-neglect
- Mental Capacity assessment

Independent Advocacy

The review highlighted the importance of the use of independent advocacy for adults at risk when adult safeguarding concerns have been raised.
Under the Care Act, The advocacy duty will apply from the point of first contact with the local authority and at any subsequent stage of the assessment, planning, care review, safeguarding enquiry or safeguarding adult review. If it appears to the authority that a person has care and support needs, then a judgement must be made as to: whether that person has substantial difficulty in being involved, and if there is an absence of an appropriate individual to support them. An independent advocate must be appointed to support and represent the person for the purpose of assisting their involvement if these two conditions are met and if the individual is required to take part in one or more of the following processes described in the Care Act:

- a needs assessment
- the preparation of a care and support or support plan / a review of a care and support or support plan
- a safeguarding enquiry
- a safeguarding adult review

There is a 7 minute briefing available here about Swindon Advocacy Movement.

Swindon Safeguarding Partnership

Learning Leaflet

Safeguarding Adult Review:
Brenda
July 2022

Multi Agency Meetings

Multi-agency working is key to supporting people who are Self Neglecting. Agencies have a duty to respond to abuse and neglect under the Care Act 2014. Key professionals from any agency or organisation can call Multi-Agency meetings for a person who self-neglects and who they are concerned about in their service. Actions set in a Multi-Agency meeting should be based on the person-centred risk assessment and contribution from all key professionals. These should be utilised where there are concerns that a client may decline care despite their high level of need.

Brenda was a 75 year old female who passed away at GWH on 03/02/2021. She experienced self neglect, depression and a number of physical health conditions. In June 2021 a SAR was undertaken following Brenda's death and key areas for learning were identified.

This learning leaflet sets out these key areas for learning. These areas have also been incorporated into the SSP strategic plan and the Learning and Development offer, the outcomes of which will be monitored to ensure they are consistent with the learning to improve frontline practice.

Assessing capacity including executive capacity

The Mental Capacity Act 2005 (MCA) is designed to protect and empower individuals aged 16 and over and help to safeguard the human rights of people who lack (or may lack) mental capacity to make decisions about their care and treatment.

It is important to consider capacity when self-neglect is suspected. However, always remember the MCA principle of assuming capacity. This means there is an expectation for professional curiosity and the testing of executive and functional decision-making capability and capacity for change.

Research in Practice have a resource on MCA and Self Neglect here

Safeguarding Supervision

e review highlights the need to ensure that safeguarding support mechanisms in place including safeguarding supervision where escalation and acting without consent can be considered and actions agreed.

There is a 7 minute briefing on Supervision on the SSP website on Supervision and Staff Resilience. The SSP also provides training on Safeguarding Supervision. More information can be found here.

Self Neglect

The term Self Neglect can cover a wide range of behaviours such as neglecting to care for one's personal hygiene, health or surroundings. it can also include behaviour such as hoarding.
The SSP Self Neglect policy and guidance and the Hoarding guidance can be downloaded from our website. The SSP provide training on Self Neglect for anyone working with vulnerable adults to develop an understanding of self-neglect and the complex issues that can impact a persons ability to make decisions. This training will look at how to balance addressing the issue of self-neglect with an individual's right to private life and health and how to make safe decisions. Click here.

The Care Act

The main principle of the Care Act 2014 is to help to improve people's independence and wellbeing and for care providers and givers to promote a person-centred approach to the care and support they provide

This review recommends that practitioners review their knowledge of key elements of the Care Act 2014. assessment, representation, the wellbeing principle, Section 19. A summary of the Care Act 2015. can be found here and the full Care Act can be found here.

Swindon Safeguarding Partnership

SAR Brian

Brian was a 43-year-old white British man who had mental health needs and a history of drug use. He lived alone in a flat, where he died in a fire on 7th February 2022. From July 2020 until his death, Brian was in contact with several agencies including the police, the ambulance service, mental and physical health services, and specialist drug services in response to self-neglect and drug dependency. Agencies struggled to engage with Brian who spent periods of time away from his flat, staying in hotels.

Brian had mental health needs and a long history of poly-substance misuse, particularly heroin and cannabis, with alcohol misuse also noted. He had continued to use drugs and alcohol while also taking methadone. Brian had been in prison on several times.

Brian was considered by Avon and Wiltshire Mental Health Partnership Trust (AWP) to be at risk of harming himself from misadventure if his mental health presentation deteriorated. Drug use was found to worsen his mental health and increase his delusional paranoid thoughts. In 2020 Brian was diagnosed with autism spectrum disorder (ASD). He presented at this time with some ongoing depressive symptoms and was involved with probation services.

The reported noted that the reports of the level of hoarding in Brian's flat before and after the fire are inconsistent and suggest that the understanding and recognition of hoarding and of the need for intervention may need to be improved.

Key Findings

- Lack of Multi-agency response to Brian ’s needs.
- Understanding of circumstances which may be predictive of poor outcomes and using these to inform practice
- Exploring the effects of traumatic events on Brian
- Operational realisation of Brian ’s diagnosis of ASD
- Risk assessments
- Suicide safety plans
- Understanding hoarding
- There was an over-reliance on AWP for all care needs
- Mental capacity.
- Effective practice for working with people who self-neglect

Learning Leaflet
Safeguarding Adult Review: RL
September 2022

Trauma Informed Practice

Trauma-Informed Practice is a strengths-based approach, which seeks to understand and respond to the impact of trauma on people's lives. The approach emphasises physical, psychological, and emotional safety for everyone and aims to empower individuals to re-establish control of their lives.
Trauma is common across the entire population, but evidence shows there is an increased likelihood that people using alcohol/drugs have experienced trauma and adversity. If your role or service supports people using alcohol/drugs, realising the increased likelihood of traumatic experiences for the people you support opens up greater opportunities for delivering trauma-informed care and support

NHS Education for Scotland has produced guidance on this theme can be accessed here

Multi Agency Working

The evidence base for best practice in working with adults highlights the importance of interagency communication and collaboration, coordinated by a lead agency and key worker who oversees this work. A comprehensive approach to information sharing is important to ensure each agency/service has a holistic view of what is happening with an individual.

It is recommended that multi-agency meetings are used to pool information as well as risk and mental capacity assessments, to agree a risk management plan and to consider legal options.

Brian was a 43-year-old white British man who had mental health needs and a history of drug use. He lived alone in a flat, where he died in a fire on 7th February 2021. In January 2022 a SAR was undertaken following Brian's death and key areas for learning were identified.
This learning leaflet sets out these key areas for learning. These areas have also been incorporated into the SSP strategic plan and the Learning and Development offer, the outcomes of which will be monitored to ensure they are consistent with the learning to improve frontline practice.

Stoke and Staffordshire "Andrew" SAR and similarities to this review

Key themes from this review included:
Multi agency approach – communication but not joined up action
Understanding impact of substance dependency on assessing capacity including impact of trauma and life
Events.
Lack of escalation processes of concerns and use of legal powers to support adult to make some positive changes such as Environmental Health due to hoarding
Listen to audio overview here

Alcohol Change UK 2019 report

This report identifies some common characteristics among the adults whose deaths resulted in the SARs and considers how their alcohol misuse was perceived by the practitioners who were working with them. It reveals the extent to which alcohol is a contributory factor in a number of tragic incidents and highlights some key themes that can inform improved future practice, such as better multiagency working, stronger risk assessments, and improved understanding and training for practitioners to help them better identify and support, in a non-stigmatising way, vulnerable people who are experiencing alcohol harm. It also considers these cases in the context of the law and discusses how practitioners could better apply the relevant legislation to similar situations, as well as how the current guidance could better address the issue of alcohol-related self-neglect.
Learning from Tragedies - An analysis of alcohol-related deaths

Substance dependency and mental capacity

The Mental Capacity Act 2005 (MCA) allows decisions to be made or actions to be taken on behalf of people who are unable to make decisions for themselves, perhaps because of a drug, alcohol or substance addiction or intoxication.

ASD and mental capacity

The impact of autism should be considered when assessing under the Mental Capacity Act 2005 or the Mental Health Act 2007.
For example, someone with autism may have good theoretical knowledge about an issue and appear to have capacity, but in fact
are not able to retain or weigh up the information. SCIE have produced guidance "Autism: Improving access to social care for adult"s including assessment which can be found here

What did the SSP do following SARs Brenda and Brian?

- Promoted Self Neglect guidance across the partnership to improve awareness
- Published Hoarding Guidance September 2022
- Delivered multi-agency Self-Neglect training modules
- Developed guidance and learning briefs around multi agency meetings
- Created a formal Self Neglect sub group of the SSP to develop a strategy, look at pathways, develop a data set and improve understanding of range of services supporting people arcos Swindon who are self neglecting and hoarding
- Webinar / conference focussing on Self Neglect

What can you do?

- Attend training
- Share policy documents within your setting
- Share examples of best practice and success stories

Swindon Multi Agency Policy and Guidance on Responding to Self-Neglect

Helen Jones

Safeguarding Development Manager

Swindon Multi Agency Policy and Guidance on Responding to Self-Neglect

The Policy and Guidance on Responding to Self-Neglect is on the Swindon Strategic Partnership website at:

Swindon Policy and Guidance on responding to self-neglect

The Policy and Guidance was developed through a multi-agency working group with representatives from agencies and organisations on the Swindon Strategic Partnership, including Police, BSW ICB, Local Authority, Health, Voluntary Sector and others.

Swindon Multi Agency Policy and Guidance on Responding to Self-Neglect - SARs

Three recently completed **Safeguarding Adults Reviews (SARs)** have occurred in Swindon in which self-neglect was a major point of concern.

Recommendations from these SARs place an emphasis on the importance of multi-disciplinary risk management and professionals working together at an early stage to support adults experiencing self-neglect. The SARs for Terry, Kieran and Brenda can be accessed here here

The National Review of 231 SARs across England identified that **45% of the cases involved self-neglect**

Part 1 – Self-Neglect Policy

- The Legal Framework
- What is Self-Neglect
- Prevention
- Indicators of Self-Neglect and reasons why people may self-neglect
- What needs to be considered by professionals when working with self-neglect cases
  - A person centred approach
  - Person Centred Assessment of Risk
  - Assessing Mental Capacity
  - Professional Curiosity
  - Engaging with people who self-neglect

Part 2 - Guidance on responding to Self-Neglect cases

- Pathways for Self-Neglect
  - Professionals Meeting
  - Referral to Adult Social Care
  - Referral to Adult Safeguarding
  - Referral to Risk Enablement Panel (REP)
  - Referral to Children's Safeguarding (MASH)

- Key agencies, their role and responsibilities

Self-Neglect Policy and Guidance - Appendices

Appendix 1: Self-Neglect Risk Assessment Guidance and Tool

Appendix 2: Legal Frameworks for partner agencies in relation to Self-Neglect

Appendix 3: Proposed Agenda Template for Professionals Self-Neglect Meeting

Appendix 4: Directory / Useful Contacts

Appendix 5: Clutter Scale Rating (for Hoarding cases)

Appendix 6: Other resources to inform working on self-neglect cases

Appendix 7: Self-Neglect – Swindon case study stories

Self-Neglect – the definition

The Care Act (2014) Guidance advises that 'self-neglect' covers a wide range of behaviour including neglecting to care for one's personal hygiene, health or surroundings, and includes behaviour such as hoarding.

Partner agencies should think broadly on what may constitute self-neglect and what pathways may be available to address concerns.

'Hoarding' is only one of the behaviours that fall into this category but it is often used almost as a synonym for self-neglect.

What the research tells us

- Self-neglect is a spectrum of behaviours, with mental, physical, social and environmental factors interacting and affecting an adult's ability to care for themselves.

- The adult may initially be fully able to care for themselves, but as problems such as chronic illness develop, the person may gradually lose the ability to perform activities of daily living.

How this Policy and Guidance will help professionals to respond to cases of self-neglect

- Professionals need to be alert to these changes to fulfil their duty to prevent a situation from escalating and to protect the adult from risk to their life and dignity, but they also have to show respect for the adult's life experience and autonomy.

- Making decisions based on these competing moral imperatives is not easy and this policy gives practitioners:
  - **ideas for reflection and**
  - **tools to make better judgements on how and when to intervene in another person's life.**

Reasons for Self-Neglect and impact on adult's life

Reasons for self-neglect are often complex but so is the impact on the adult's life.

Self-neglect may impact on a person's health, wellbeing or living conditions and may have a negative impact on other aspects of their life. Without **early intervention**, existing health problems may worsen.

- Neglect of personal hygiene (**physical factor**) may lead to social difficulties and isolation (**social factor**), or physical/mental health breakdown and cognitive difficulties (**mental factors**).
- Dilapidated property or excess rubbish (**environmental factor**) can become infested and can be a fire risk, which is a risk to the adult, family, neighbours and others.

What the Self-Neglect Guidance will help you to do:

- Define different types of self-neglect
- Feel confident in identifying self-neglect
- Know what you can do to support people who self-neglect
- Know your responsibilities when working with someone who self-neglects

Self-Neglect Risk Assessment and Tool

The Self-Neglect Risk Assessment and Tool included with this Guidance at Appendix 1 will be helpful to Providers for responding to cases of self-neglect.

The Clutter Scale Rating

Clutter Scale Rating: BEDROOM

Please select the photo that most accurately reflects the amount of clutter in the bedroom(s)

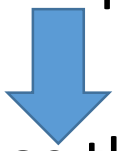
Clutter Scale Rating: LIVING ROOM

Please select the photo that most accurately reflects the amount of clutter in the living room

Self Neglect - Prevention

Initially, the adult may be living independently and fully able to care for themselves

As time progresses or as a result of key events in their lives (such as the death of significant others) they may develop physical or mental problems such as chronic illness, restrictions of mobility or a dependence on substances and as a result, lose the ability to care for themselves. This often happens gradually over time, but may happen more quickly, and mean that the person is **at risk of significant harm or death**



Professionals may notice the changes as the individual not looking after themselves or their home environment quite as well as they used to. As time moves on, this may lead to a lack of ability to complete basic tasks of self-care and daily living such as personal care, food preparation or care for one's home environment.

All practitioners should be alert to these changes when they see them or visit a person in their home.

A person-centred approach

- Key to effective interventions is building relationships to effectively engage with people without causing distress, reserving the use of legal powers to where they are proportionate and essential.
- Things to consider when working with people who self-neglect, for instance
  - Work at an individual's own pace and set achievable goals (smaller steps rather than complete life changes)
  - Support the person to feel 'in control' of their life and involve them in decisions
- Balancing autonomy and protection is important. An assessment of a person's mental state is important and mental capacity assessments are key in professional decision making.

Engaging with people who self-neglect

- The nature of self-neglect cases means there is an increased likelihood that the person may refuse support when it is first offered.
- Initial non-engagement should not result in no further action
- Consider different ways to engage the person, for example:
  - Go on a **joint visit** with someone that the individual knows, trusts and feels comfortable with. This could be a family member, friend or another professional.
  - **Contact other professionals** who are in contact with the person (GP, day centre workers, cleaners, etc.). They may have suggestions about how best to engage with the individual.
- **And remember Professional Curiosity**

Professional Curiosity

Swindon Safeguarding Partnership Professional Curiosity Resource Pack is at:
https://safeguardingpartnership.swindon.gov.uk/downloads/file/802/resource_pack_-_professional_curiosity

Self-Neglect Professionals Meetings

- Agencies have a duty to respond to abuse and neglect under the Care Act 2014. Key professionals from any agency or organisation can call **Self-Neglect Professionals meetings** for a person who self-neglects and who they are concerned about in their service.
- Meeting or discussions will usually be coordinated by the agency which is most involved in the main area of the person's self-neglecting behaviour.
- Multi Agency Meeting Guidance document including templates for agenda and minutes available here
- The purpose of the **Self-Neglect Professionals meeting** is to:
  - Discuss risks
  - Identify the most appropriate lead
  - Implement a plan which provides the most appropriate person-centred response to manage risk to the person.

Other pathways for Practitioners to follow…

- **Referral to Adult Social Care**

  Where care needs are identified by a professional, a referral to Adult Social Care should be made to enable an assessment of these needs so that appropriate care can be put into place.

- **Referral to Adult Safeguarding**
  - Where a person has been identified as having care and support needs under the Care Act, and is at risk of harm, self-neglect or abuse, a referral should be made to Adult Safeguarding.

- **Referral to Risk Enablement Panel (REP)**
  - Where a person declines to engage with services and has the mental capacity to make the decision, if the adult is at risk of harm, a referral to the REP should be considered (when doesn't meet criteria for S42).
  - 7 minute briefing on REP can be found on SSP website

- **Referral to Children's Safeguarding (MASH)**
  - If there is concern for the safety and wellbeing of a child or young person who may be at risk, a referral to the MASH must be considered.

Case Study - self-neglect & hoarding

Kay Giblett

Environmental Health Officer

Housing & Environmental Protection Team

(This presentation was not recorded)

Lengthy, challenging cases!

Further information and guidance regarding assistance and powers available to Environmental Health can be found in the Self-neglect – Multi-agency policy and guidance on responding to self-neglect - Swindon Safeguarding Partnership and appendices.

Questions or Comments

Team contact : housingep@swindon.gov.uk

My contact details : kgiblett@swindon.gov.uk

Swindon Multi Agency Policy and Guidance on Hoarding

Helen Jones

Safeguarding Development Manager

Swindon Multi Agency Policy and Guidance on Hoarding

This document sets out a framework for collaborative multi-agency working in Swindon using a ‘person centred approach’ model to support individuals demonstrating hoarding behaviours.

It should be used alongside the Swindon Multi Agency Policy and Guidance on Responding to Self-Neglect at: SSP Policy and Guidance on Responding to Self-Neglect

Hoarding Guidance Content

- Information Sharing
- Definition of Hoarding
- Types of hoarding and general characteristics of hoarding
- Managing Expectations
- Legislation relevant to hoarding behaviours
- Fire safety
- Multi-agency response
- How to assess hoarding
- Communication

Hoarding Guidance - Appendices

Appendix 1: Self-Neglect Risk Assessment Guidance and Tool

Appendix 2: Clutter Scale Rating (for Hoarding cases)

Appendix 3: Glossary of Legal Powers

Hoarding – the definition

The Care Act (2014) Guidance advises that 'self-neglect' covers a wide range of behaviour including neglecting to care for one's personal hygiene, health or surroundings, and includes behaviour such as hoarding.

'Hoarding is the excessive collection and retention of any material to the point that living space is not able to be used for its intended purpose.'

What is Hoarding?

- Hoarding disorder is a persistent difficulty in discarding or parting with possessions. A person with a hoarding disorder may experience distress at the thought of getting rid of the items or simply be unable, either physically or through other health related factors, to get rid of items despite an acknowledgment that changes need to be made. They will have an excessive accumulation of items, regardless of actual financial value.

- Hoarding is considered a standalone mental health disorder and is included in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) 2013. However, hoarding can also be a symptom of other medical disorders; it is not a lifestyle choice.

Aims of the Hoarding Guidance

- Create a safer and healthier environment for the individual and others affected by the hoarding behaviour, e.g. the person, neighbours, family etc.
- Deal with incidents of hoarding in a consistent evidence-based approach, with a structured multi-agency pathway.
- Maximise the use of existing services and resources and reduce the need for enforcement action.
- Ensure that when interventions are required, there is a clear process tailored to the individual, using a holistic approach. The intervention should include a combination of therapeutic and enforcement tools to reach the required outcome. This needs to include monitoring after resolution to prevent re-occurrence.
- Ensure the individual with hoarding behaviour is fully engaged in the process and include family and peer support to achieve this where possible.
- Establish best practice and share case studies that relate to hoarding behaviour to improve knowledge of hoarding, successful interventions and changes in legislation.
- Enable staff from all agencies to work in partnership in order to support where possible a successful outcome for all involved.

How the Hoarding guidance can help you:

- There are a range of organisations which are involved in dealing with the effects of hoarding behaviour. It is recognised that multiple factors (including mental ill health) can play a part in these behaviours, and is evident that a purely enforcement approach to hoarding often only results in a temporary resolution only for the behaviour to reoccur within a relatively short period of time.

- This Swindon Multi-Agency Hoarding Guidance supports practitioners from different agencies and organisations to respond to and work with individuals with hoarding behaviours, using a multi-agency approach.

Multi-agency response and pathways for responding to cases of hoarding

- The response to hoarding, as any other professional response, needs to be proportionate. Some situations may be best addressed by advice and information to the person or their representative, or by some support or assessment by a single person or agency who the person is most familiar with.

- From a certain risk level however, responses need to be coordinated between agencies in order to protect the person better and to manage risk appropriately. Where there is evidence that an individual may be at immediate risk from self-neglect or hoarding, a referral should be made to Adult Safeguarding and a social work assessment visit must take place within 24 hours to assess the level of risk. The **SSP Self-Neglect and Hoarding Risk Assessment is at Appendix 1.**

- Professional judgement will need to be applied when deciding on the most appropriate pathway to secure professional multi-agency collaboration and appropriate risk management.

- Multi-agency collaboration is the starting point.

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Multi-Agency Self-Neglect and Hoarding Risk Assessment Tool

The Multi-Agency Self-Neglect and Hoarding Risk Assessment Tool included with this Guidance at Appendix 1 will be helpful to practitioners for responding to cases of self-neglect.

The Clutter Scale Rating

Clutter Scale Rating: BEDROOM

Please select the photo that most accurately reflects the amount of clutter in the bedroom(s)

Clutter Scale Rating: LIVING ROOM

Please select the photo that most accurately reflects the amount of clutter in the living room

Professional Curiosity

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Case Study: self-neglect

- **Kati Wood- Healthy Communities Manager**
- **Live Well Swindon**

Maggie: I'm on top of things. I'm organising a house swap and moving to Oxford. I've seen a lovely house that will make all the difference to me. I love my job and I am good at it. I love my dogs. Without them I would never have coped. I cant keep on top of things. Nothing changes. I know my life is chaotic but I am so good at hiding it, I start to believe my own lies. I had a really traumatic break up in Swindon, if I could leave here I would be better. I feel so angry. I cant stand my landlord – things have broken down there and things are getting worse with my son. He says I should take the dogs out but I cant because I have tennis elbow and they yank the lead. I'm buying things I don't need because I want things to look better, make my house look nice and live a nicer life. But I know I cant change. I have no motivation. When my boiler broke I stopped washing myself. I'm not going to ask for help – they will take my dogs away.

Meet Maggie

What do we see and hear?

Maggie functions effectively in her work and pretends that life is going well to the outside world. Her home is in a poor state and her lifestyle is chaotic. She has three large dogs who don't get walked and either use the house or garden as their toilet. Relationship with landlord is failing. Neighbours complain and are anxious that Maggie's house will catch fire. Maggie has aspirations for a different life but is not motivated to make changes, other than buying large items that would make her home or garden look more impressive to passers by. These never make it to their place in her home or garden. She has developed the ability to show that things are going well, even when they aren't. Her walkways are cluttered and where we see carpet, it is covered in peat that was delivered for the garden – but never made it out of the house. Maggie walks around in her pyjamas and barefoot, her feet are dirty, Maggie has no hot water and is not motivated to manage her personal hygiene. She is at risk of eviction but believes that she can organis[illegible]use swap and escape.

Maggie needs to find the right support to improve her mental health and manage her anger which is having a destructive impact on her relationships.

Connection

Texts were exchanged before Adele met Maggie on the doorstep – no pressure to go inside.

After some rapport was built up –Maggie let Adele look through the window.

Adele was curious but never judgemental.

Adele gave Maggie time and space to use her own words to describe her situation

Relationship

Adele came to understand how Maggie was operating. She has a pretend life where everything is great, her house is full of lovely things, she is confident, a successful home based worker for a local authority in London. By slowly building trust and being tenacious but non judgemental, whilst taking things at Maggie's pace, Adele was allowed to see this with her own eyes as Maggie shared her truth. As the trust grew – Adele was able to share this trusting relationship with other team members.

Action

Initial objective – Safety, clear walkways throughout property, remove peat to discourage dogs from fouling in house, liaise with housing agency/landlord to arrange boiler repair. This was completed largely by Live Well Navigators but with an approach that encouraged Maggie to participate in the activity, which she did. Maggie has also engaged with a counselling service to talk through her emotional issues.

Next steps

Baby steps for Maggie to get her property into a condition where it would be suitable for a house swap. This will require regular, non judgmental visits where Maggie is supported to co-produce a plan for change, and is regularly supported to achieve her objectives. We can also look for signs of Maggie slipping into habits where she abandons self care and address these as and when needed. We will also explore options for Maggie's dogs (volunteer dog walker for example) to improve their quality of life.

Sandie: I grew up in London just after the war. Everything was still being rationed so “waste not want not” and “make do and mend” were sayings that were instilled in me from an early age. My mum kept everything. I have lost so many people that were important to me my best friend – she was wonderful, we lived together, my mum, so many others have gone, there is no one left. I don’t trust people who say they want to help, I don’t want people coming into my home. I don’t see what the problem is – I am managing ok. I don’t see that I am causing any problems at all. I hate the idea of landfill – it really frightens me so I do keep a bit of plastic in the flat. My intention is to rinse it out and pop it into the recycling, but my mobility isn’t what it was, so it does tend to mount up a bit. I cant pay for someone to come in here and help me, even if I could afford it I would be too ashamed. If I feel lonely I can go to the lounge and chat to people.

Meet Sandie

How Sandie came to our attention.

Sandie was referred to us as she would not answer her door to Social Workers. No one really knew the extent of the hoarding but she was upsetting neighbours at the sheltered accommodation where she lived because she kept setting off her fire alarm and they noticed an unpleasant smell coming from her property.

What do we see and hear?

Sandie wasn’t aware of a problem and wasn’t keen to let us into her home. Sandie is motivated by her aspirations to protect the planet. Sandie feels alone and bereft. Sandie shakes uncontrollably and may have an undiagnosed health condition. Sandie cannot make steps towards change on her own because she feels shame. Having control over her own space and her possessions are important to her, but the items that are causing her home to be less safe and functional are not items that she is emotionally attached to. She does place significance on the appropriate disposal of items.

Connection

Adele asked the warden how she might meet Sandie after failed attempts to make contact. Sandie does her laundry every Tuesday, so Adele placed herself in the laundry room on that day to initiate a conversation. Sandie shared her story with Adele. When the laundry was finished Adele offered to carry it back to her flat. Adele asked Sandie if she could pop her head around the door of the flat – just to be sure that it was safe. She emphasised that there was no judgement. Adele then asked if she could pop in. She told Sandie that at any moment– she could ask Adele to leave. Sandie let Adele in. The floor, bathroom, bedroom and kitchen are covered in have used plastic bottles of milk. Adele can smell the sour milk. The bath/shower is full of toilet rolls and it would not be possible for Sandie to shower. Sandie buys more food than she needs and there are bags of rotton food around the home.

Action

Support Sandie to clear some of the floor space to reduce the risk of falls and ensure safe passage through the flat. Clear the bathroom so that Sandie can wash and maintain her personal hygiene.
Organise for the Fire service (Safe and Well) to visit and install smoke detectors.
Build rapport with Sandie to establish a relationship between her and the Navigators.
Regular visits and practical support, honouring the importance Sandie places on recycling.

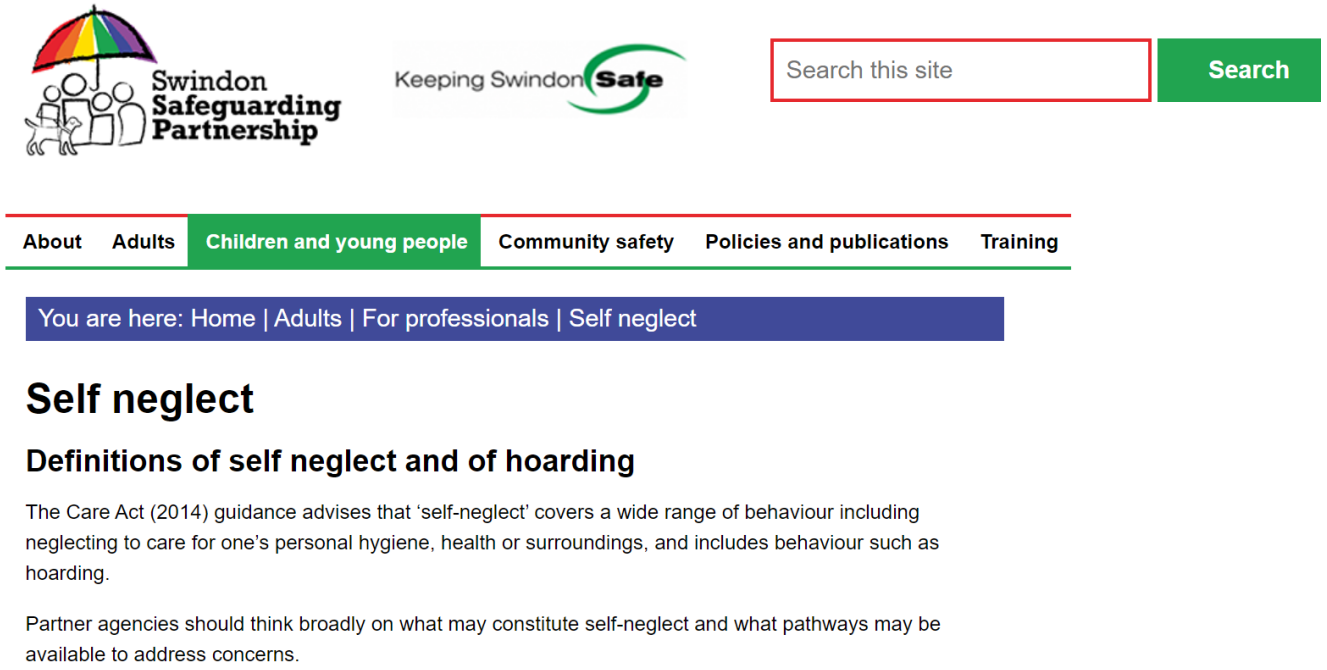
Next steps

Sandie is ready for her home environment to change, but not quite ready to change her habits to achieve this and her mobility creates another barrier. We continue to visit Sandie to ensure her walkways are clear and can look at alternatives to her current shopping habits e.g. milk/shopping deliveries. We will also look to support Sandie to engage with other professionals to ensure that her care needs are met.

Contact details-

Email : livewell@swindon.gov.uk
Our referral form can be found here: Live Well Swindon Hub referral form | Swindon Borough Council

SSP Training and Resources



Webpage for professionals: Self neglect - Swindon Safeguarding Partnership
SSP Training: Training Information - Swindon Safeguarding Partnership
Resources to assist in risk assessment and responding to SN: Appendices – Self-neglect – Multi-agency policy and guidance on responding to self-neglect - Swindon Safeguarding Partnership

POLL

What one action will you take from this to either apply to your direct practice or apply to your service area if you have line management responsibilities?

Please put your comments in the chat.