

Learning Support Document

Self-Neglect and Hoarding

Foreword

In the East of England we are proud of our collaborative work and have put considerable time and effort into our Sector Led Improvement Programme. This has supported real improvements and innovation both locally and regionally.

Adult Social Services has distinctive values in our duty to safeguard, to promote independence and to stand up for our communities, putting the people we serve first in our improvement work and all that we do. This is grounded in the values and practice of our frontline teams and their ability to develop, share, and learn from good practice at local, regional and national levels. Papers such as this positively promote such sharing and learning and prompt discussion and further development of practice across our services. I would encourage you to use the good practice within this paper for your own training and guidance materials and to use it to initiate discussions regarding self-neglect and hoarding within your authority.

Please do not hesitate to contact Helen Duncan who is the chair of the Eastern Region Safeguarding Network if you would like to discuss the content or further issues that it raises; Helen.Duncan@Cambridgeshire.gov.uk. I hope that you find it a useful resource.

Nick Presmeg

Regional Chair of the Eastern Region ADASS Branch

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1 Introduction

This document was funded by the ADASS (Association of Directors of Adult Social Services) Eastern Region in 2019 and initiated by the ADASS Eastern Region Safeguarding Adults Network following identification of the complexities of working with Adults at Risk who self-neglect. It is aimed primarily at adult social services social work practitioners and managers employed in statutory roles but its content is relevant to all professionals who may work with adults who self-neglect and/ or hoard.

Case studies are used as examples of how to work effectively with people who self-neglect and or/ hoard and key points of good practice are identified. These have been taken from research studies and particularly from the work of Michael-Preston Shoot, Suzy Braye and David Orr.

A document like this can never be comprehensive. A broad range of case studies have been chosen but they cannot cover every set of circumstances that practitioners will encounter in their work. The key points of good practice, however, should be applicable to other situations and should equip practitioners with a set of principles to use in their work.

2 What is self-neglect?

The Care and Support Statutory Guidance to the Care Act (2014) defines self-neglect as a situation, “Where someone demonstrates lack of care for themselves and or their environment and refuses assistance or services. It can be long-standing or recent”.

According to SCIE (Social Care Institute of Excellence), “Self-neglect is an extreme lack of self-care, it is sometimes associated with hoarding and may be a result of other issues such as addictions”. It can include:

- Lack of self-care to an extent that it threatens personal health and safety
- Neglecting to care for one’s personal hygiene, health or surroundings
- Inability to avoid harm as a result of self-neglect
- Failure to seek help or access services to meet health and social care needs
- Unwillingness to manage one’s personal affairs

It is important to remember that self-neglect is not about someone being unable to care for themselves. Many people who come to the attention of adult social services do so because they are no longer able to perform the activities of daily living, such as attending to their personal care or nutrition. In these situations, an assessment under the Care Act and the provision of services will ensure that their needs are met.

Self-neglect is when someone is unwilling, for a number of reasons, to care for themselves.

3 Self-neglect and social care legislation

Self-neglect is included in the Care and Support Statutory Guidance to the Care Act (2014) in relation to:

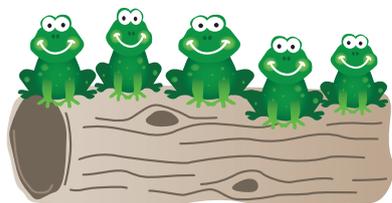
- The duty to promote well-being. The guidance specifically refers to the need to work alongside people who self-neglect to understanding how their past experiences influence their current behaviours. The guidance states (s 1.12) that, “The duty to promote wellbeing applies equally to those who, for a variety of reasons, may be difficult to engage”.
- Adult safeguarding. Self-neglect is included as one the categories of abuse or neglect that might require an adult safeguarding intervention. Additionally, the guidance promotes a general need to protect people from abuse and neglect, including self-neglect, regardless whether or not an adult safeguarding concern has been identified.
- The need to ensure that any restrictions on the individual’s rights or freedom of action are kept to the minimum necessary

4 Why do people self-neglect?

There are many possible reasons but some examples are:

- Traumatic life experiences. Sometimes self-neglect and especially hoarding are associated with loss in earlier life. Self-neglect can also be a form of control for people who have had little control over what has previously happened to them.
- Brain injury, sometimes related to alcohol consumption, dementia or other mental or physical health problems.
- Addictions, where other motivations and interests have been subsumed.

5 Mental capacity and self-neglect



**“Five frogs are sitting on a log. One decides to jump off.
How many frogs are now sitting on the log?”**

People who neglect themselves often decline help. A particular challenge is that adults are assumed to have the mental capacity to make their own decisions about how they live unless there are reasons to doubt this. Mental Capacity assessments that are decision and time specific are therefore an essential component of working with people who self-neglect.

Research studies have identified that the cognitive processes used in making decisions can be divided into two:

- **Decisional Capacity:** the ability to make a decision
- **Executive Capacity:** the ability to put that decision into action.

It is possible to have the capacity to make a decision (Decisional Capacity) but to lack the capacity to act upon that decision (Executive Capacity). For example, you may know that you should walk to work since it will be good for your health. Doing so, unfortunately, is another matter.

The law in the form of the Mental Capacity Act, however, does not explicitly recognise this distinction. It does, however, include the concept of a person’s ability to use and weigh information within the regulations that cover Deprivation of Liberty Safeguards. Consequently, the law does make room for a person being able to weigh up information to reach a decision (Decisional Capacity) but not being able to use or act upon that information (Executive Capacity).

An answer to the “Frog Question” is provided at the end of this guidance.

6 Case studies

Working with people who self-neglect can be extremely challenging. The evidence from research and from successful practice is that it is important to try to engage with people who self-neglect to understand them and to develop a relationship with them. Keep offering support even if it is refused several times. It is also important to recognise that any intervention will have limitations and that reducing, rather than removing, risk and harm may be a more realistic aim.

It is important to find out what the reasons are for someone's self-neglect, as the case study of John shows.

John: non-compliance with medical treatment

John was 30 years old. He lived alone and had never been in touch with adult social services before. John had diabetes and his GP became increasingly concerned about him. John was attending diabetes clinics irregularly despite numerous reminders, he was not following advice about what to eat and how best to manage diabetes, he often lost his blood sugar monitoring equipment and it was unclear if he was taking medication as prescribed or even at all.

John's GP contacted the local MASH (Multi-Agency Safeguarding Hub) to raise an adult safeguarding concern about this. John's GP was worried that John was neglecting himself and that if he continued to do so, he might become seriously ill or die. The GP said that John needed care and support and also that he was diagnosed with autism. Despite this, the GP said that there was no reason to doubt John's mental capacity to understand the need to manage his diabetes and the potential consequences of not doing so.

What can we learn from this short story?

Many people who self-neglect have not previously been in contact with adult social services. There are several reasons for this. It may be that natural support networks, which previously meant that there was no need for additional help, have broken down or can no longer provide the level of support required. It may be that the person has not wanted outside help. It may be that there has been an increase in the person's needs or in the impact of their unwillingness to meet these themselves. It may be that there has been a crisis that has led to the intervention of other services such as the police or the fire service. It may be that, as in this case, other people or services that support someone who self-neglects have reached a point where they have exhausted all their usual ways of working.

Health professionals such as GPs or district nurses are often the first people to identify that someone may be self-neglecting or who may have social care needs. Everyone should be registered with a GP and may be called for appointments, tests and checks.

Referrals may come in through different routes. In this case, the MASH was used since the GP was more familiar with it. Many people do not understand how social services work and may use different points of access.

What happened next?

Following the GP's referral to the MASH, a decision was made that a Multi-Agency Risk Management Meeting should be held to agree and coordinate actions to support John. This meeting was coordinated by a social worker and included:

- The GP
- The Practice Nurse from the GP Surgery
- The Safeguarding Lead from the local NHS Trust
- The Diabetes Lead from the local NHS Trust
- The Social Worker
- John was invited to the meeting but did not attend but the social worker had spoken to him and had been told that John found make travelling arrangements to be difficult and expensive.

The following actions were carried out:

- The Practice Nurse liaised with the pharmacy to understand John's collection pattern of his medication and link his visits to the pharmacy with his appointments at the surgery, as they were next door to each other.
- John was offered community diabetes appointments with the community consultant and specialist diabetes nurses who could visit John at his home were made available.
- John was given information on less expensive transport options to encourage his attendance at appointments.
- Following these efforts to understand John's situation and to facilitate his participation in his treatment for diabetes, John agreed to attend a follow up review meeting by telephone.
- After this, the social worker took advice from the Principal Social Worker since the treatment of John's diabetes did not appear to meet the threshold for MARM, as it was purely related to health and was not a multi-agency risk. In future it could be managed through health escalation procedures.

What are the key points of good practice and learning from this case example?

- **Involving the right people.** In addition to the GP and the practice nurse, professional advisors from the NHS Foundation Trust were involved. They were able to offer expert advice on diabetes treatment and to access other specialist services such as a community consultant and nurses. This utilisation of other resources and expertise is one of the reasons by multi-agency working is essential to support people who self-neglect.
- **Understanding the reasons for self-neglect.** Even though it was not apparent initially, John struggled with travelling back and forth between appointments. John could not easily access public transport and could not easily afford the cost of taxis. Changes were made to the way the diabetes treatment service was provided to him to reduce the number and cost of journeys he had to make.

- **Find alternative ways to help people who self-neglect to participate.** John would not or could not attend the meetings in person but was willing to take part by telephone.
- **Coordination.** Meeting John's health needs required a more sophisticated intervention by health services. The recognition of this and agreement of the actions required was coordinated by a social worker. It is not always the responsibility of social services to carry out an intervention with someone who self neglects, but sometimes it requires a social worker to bring the right people together.

Sometimes, the best that can be achieved is to reduce the risks and harm that someone who self-neglects faces, as the next case study about David illustrates.

David: alcohol dependency and refusing support

David was 69 years old and lived in a housing association flat. He was open to adult social services and had care and support needs related to long term use of alcohol. There had been a number of safeguarding concerns about self-neglect and possible financial abuse by others in the community.

David was doubly incontinent due to his use of alcohol and had accepted a care package of one call per day. David refused to have this increased, as assessed, to three calls per day, and often refused to allow carers to undertake any tasks at all. The commissioned tasks included assistance with personal care, support to make meals, support to maintain a habitable home and support with finances and ensuring utility bills were paid. David's refusal led to him sitting in faeces and urine for prolonged periods and at one point he refused personal care for a period of 27 days.

David's mobility was limited and he often spent prolonged periods sitting in a chair. David would often go to the local shop at approx. 5am, in bare feet, to buy alcohol. The shop would not allow him in but David handed his bank card to them through the window. David was also admitted to hospital a number of times due to falls in the street. When in hospital David agreed to increased care and support but did not accept this upon his discharge.

The combination of incontinence and reduced mobility led to David developing painful and infected sores which he was reluctant to have treated.

There was, however, no reason to doubt David's capacity regarding his care and support needs. David's GP also concluded that there was no reason to doubt his capacity regarding his understanding of pressure ulcers and the possible consequences of these.

A crisis point was reached when David's care provider served notice because it was concerned that the support was ineffective and because David was verbally abusing its workers.

What happened next?

David's social worker organised a Multi-Agency Risk Management Meeting attended by representatives from:

- Housing
- Drug and Alcohol Service
- District Nursing
- Adult Social Services
- Care provider

David was invited but did not attend. He was informed of the outcome of the meeting.

The following actions were carried out:

- A housing association officer visited David more regularly so offering further checks on his welfare.
- The District Nurse liaised with the tissue viability service to supply a specialist bed, a waterproof mattress and pressure cushions for chairs. This provision of this was aided by the Multi-Agency Risk Management meeting and was supported by housing following the concerns of neighbours. As a result, David's pressure ulcers began to heal.
- The Drug and Alcohol Service offered advice on the support that was available and suggested how to discuss this with David. A respectful but frank conversation about the risks of continuing to drink was had with David who remained clear he wished to continue drinking and that he wanted to remain at home.
- Consideration was given to whether or not David could be detained under the Mental Health Act (1983) to allow access to alcohol rehabilitation. It was agreed, however, that David did not meet the criteria for detention and that it would be less distressing for him if he could access alcohol rehabilitation voluntarily during his next stay in hospital.
- David made an advance decision that he did not want lifesaving health interventions and treatment. He was supported to record this decision in compliance with the Mental Capacity Act (1983) so that it would be upheld even if, at some point in the future, he lacked the mental capacity to decide.
- David agreed to give money rather than his bank card to the shop when buying alcohol, so as to safeguard him, to an extent, from financial abuse.
- The care provider felt supported and agreed to continue to provide a service to David.
- David was notified in writing that the bare wooden flooring in his property (which was difficult to keep clean and had resulted in prior complaints from neighbours regarding the smell) had to be covered with lino, free of charge. David accepted this and the care provider helped him to choose it.
- A review meeting was set to take place in three months' time. Unfortunately, David died before this, but he was at home, in line with his stated wishes, was more comfortable and died in a more dignified situation.

What are the key points of good practice and learning from this case example?

- **Multi-agency, multi-factor approaches work best.** The input of housing, district nurses, specialist tissue viability nurses, drug and alcohol services, the care provider and social services meant that a range of David's needs were met more effectively. Even though the core of the intervention was to better manage David's drinking, continence and pressure care and their associated consequences, the risk of financial abuse was reduced: attention to other risks was not lost.
- **Risk reduction and management.** The approach was to work with David to reduce the risk of harm rather than to remove it and, where possible to improve his life whilst not necessarily changing the way he lived. and he was supported to make an advance decision under the Mental Capacity Act (1983) that he wanted to refuse lifesaving treatment. David's decisions were respected, and this helped to develop a relationship with him, which meant that he was less resistant to being helped. As a result, the care provider was able to continue to support him, since its staff were no longer faced with resistance and abuse and could see that the work they were doing was helpful. Note that the offer of alcohol rehabilitation was still open to David despite his decisions: it is important to keep engaged and to keep options open since people sometimes do change their minds.
- Note also that whilst David did not attend the Multi-Agency Risk Management Meeting, he had been notified that it was taking place, what the agenda was and afterwards what the outcome was. Treating David as a partner helped to develop a more positive relationship with him, which in turn led to him being more willing to work with agencies and people involved.
- **Assertiveness.** David was told in writing that the floor in his home had to be covered in lino. He was not given a choice. The reasons were explained and, building on the more positive relationship that had been developed with him, David accepted this. Even though David was told that lino had to be fitted he was not completely disempowered and was supported to choose the lino pattern and colour that he preferred.
- **Legal literacy.** Consideration was given to whether or not to use the powers of the Mental Health Act (1983) to make David access alcohol rehabilitation support. In this case, it was concluded that the criteria for this was not met and this approach would be too distressing. In other situations, however, it may be appropriate to use coercive legislation and these approaches should be considered even if they are discounted.
- **Not all interventions have happy endings.** The multi-agency support provided to David did not prevent his death but did mean that his life was improved, that he was in less pain and he died with dignity.

Working with two people who hoard and self-neglect can present challenges because a solution for one person may not be right for the other as the case of Jane and John shows.

Jane and John: poor living conditions, multiple pets, resisting help

Jane was 60 years old and lived with her husband John. For some years there had been concerns regarding their living conditions, but each time adult social services became involved the couple cleaned up their property and the concerns decreased.

A new safeguarding referral highlighted further deterioration which was affecting Jane's health. She had attended at a Day Hospital in a severe state of self-neglect. Jane appeared unkempt; she was dressed in unwashed and oversized men's clothing; her clothes, fingernails and walking frame was covered in pet faeces; the dressings on her legs were described as filthy.

The hospital staff spoke to Jane about putting support in place for her at home, but she declined this, saying that she and her husband do not want to have other people in their house. There was no doubt that she had capacity to make her own decisions.

The Day Hospital staff did however seek advice from the Adult Safeguarding Team and Jane was allocated a safeguarding senior practitioner and a referral was made to a Local Area Co-ordinator (LAC) to build a relationship with Jane in the hope that she would allow access to their home and accept further support from other services.

The LAC arranged a joint home visit with a staff member from the Day Hospital, who knew Jane well. They met with Jane outside her house, as she wouldn't let them into the house. It was apparent even from the outside that the house was in a severe state of neglect and there was a strong smell of pet faeces. Jane still declined support, but a referral was made to the Local Authority's Environmental Health Team, due to concerns over their unsanitary living conditions. The Environmental Health Team visited the property and found the house to be squalid and severely cluttered, there was no hot running water and almost everything was covered in pet faeces. There were approximately 15 pets in the house. Jane and John were still declining any support with cleaning the house but concerns for Jane's health and wellbeing were now too great not to take any actions.

The case was brought to the local authority's hoarding panel, where the Environmental Health Team agreed to serve a Public Health Act (1936) Notice, which placed a legal duty on Jane and John to arrange for a clearance and deep cleansing of the property within 28 days of serving the notice. This was a turning point as they had to act. The Adult Safeguarding Team and LAC co-ordinated the process of supporting Jane and John and involved other services to clear and deep cleanse the property within the given timeframe. Strong relationship-based practice helped to build relationships with Jane and John. They started to engage in the process and became very involved in working with the company commissioned to carry out the clearing and cleansing work, with them present. Whilst this took longer, it was recognised that Jane and John needed to be involved so they could be responsible and part of the solution, rather than the clearance being 'done to' them.

The house was cleared and deep cleansed and Jane and John continued to engage well with services. Some of their pets have also been fostered. They are now starting to show pride in their property and have been working hard to maintain it. The community have come together to help with donations of furniture and bedding etc. John has said it was like a 'cloud has been lifted' and he is in high spirits and positive about the future. Jane found the change harder and more support with this will continue to be provided. The Safeguarding team and LAC will remain involved until a suitable time in the future. The LAC will be supporting them to also make more connections with their community.

What are the key points of good practice and learning from this case example?

- **Collecting animals can be a form of hoarding.** Sometimes animal charities need to be involved to check on their health and potentially to find suitable alternative accommodation for them.
- **Some local authorities have formal hoarding panels or have Community MARAC (Multi-Agency Risk Assessment Conferences) arrangements.** These help to instigate and coordinate multi-agency action. They are useful forums for raising concerns if you feel that you do not know what else to do.
- **Use of the law and legal literacy.** Even if social services lack the legal power to act, it does not mean that this is the case for everyone else. Not all social workers are familiar with the legislation that underpins the work of other departments or professionals. You can often find more about this in your Self Neglect and Hoarding policies and procedures.
- **Developing a relationship with people who self-neglect and hoard is vital.** Try to understand what their motivations and attachments are but be honest about what the consequences might be if there is no change.
- **Even when the law is used to force change, it is essential that you identify and take any opportunities to engage people in the intervention and to support their control and participation.** Self-neglect and hoarding can be a form of control so approaches that try to take control away will often be met with resistance and may even lead to more self-neglect and hoarding.
- **Hoarding often has a strong emotional component.** Note how John and Jane have responded differently. For John it was a relief, but Jane had a stronger negative emotional reaction and it will be important that she is supported to manage this. Jane may have experienced trauma and loss in her earlier life that left her with a gap that the animals have filled. She will need help to fill this gap again in a way that she and John can manage more effectively.
- **The problems do not go away easily.** Long-term involvement is sometimes necessary. Sometimes a change in circumstances can lead to problems as shown in the case of Sarah.

Sarah: recent decline, tenancy risk, recent arrival of a young relative

Sarah was 61 years old and lived in a one bed ground floor flat. She had been a tenant of the Council for over 35 years. The property was kept in a clean and tidy condition and there were no concerns regarding the conduct of the tenancy.

Sarah suffered from emphysema and anxiety and had a home care worker visit three times a week to help with cleaning the flat, shopping and some elements of personal care. Despite her poor health Sarah could do light cleaning and shopping and she liked to go out of the house for a walk on a regular basis. Sarah also let the home carer in.

Sarah's 15 year old grandson Wayne moved in with her following a dispute with his mother and initially slept on the sofa. The home care worker noticed that he was often in the house smoking and drinking beer with his friends. He did not appear to be attending school. When asked about this, Sarah said this was OK as she liked to have company and she would not ask him to leave.

After several weeks, the home care worker noticed that Sarah was becoming illusive and would not answer the door. She could see through the windows that the property was becoming unkempt, with dirty crockery piled up in the kitchen and clothes discarded on the floor.

The home care worker notified the housing department, which had also received complaints from neighbours about noise and the smell of drugs coming from the property.

Sarah's rent account was in arrears and despite letters and visits to the property the income officer was unable to make contact with Sarah. This was unusual since there had never been any problems before.

The home care worker did gain access to the property and noted that Sarah was now sleeping on the sofa and that Wayne was now sleeping in her bed. The property was in a poor condition and there was little food in the cupboards. Sarah said that she had no money to buy food as Wayne needed to buy computer games and beer. Rent arrears had accrued to over £1,000.

Sarah confided in the home care worker that she did not want to live this way but that Wayne had nowhere else to go and she was frightened that he would be angry if she told anyone about what was happening.

It is useful to reflect on the concerns identified since these form part of the risk assessment. Breaking the risks down like this and identifying further areas of enquiry (and specifying who will enquire and when by) helps to create an accurate picture of the situation. Targeted interventions can then be identified and implemented.

- Smoking within the home could cause Sarah's emphysema to deteriorate
- The condition of the property was worsening
- Sarah was not receiving the personal care that she required
- Wayne was not attending school
- The neighbours' reports of Anti-Social Behaviour and drug use needed to be investigated
- There were inappropriate sleeping arrangements
- Was Sarah suffering physical abuse, either from Wayne or his visitors?
- There were concerns about Sarah's mental health/anxiety
- Sarah was becoming reclusive
- Was Sarah being financially abused?
- Was there underage drinking and the possible use of drugs in the property?
- Sarah was fearful of repercussions from Wayne.

The following actions were carried out:

- A one-off deep clean of the property was paid for by adult social services
- Sarah was supported to visit her GP for a full medical check-up, review of medication and referral to a mental health worker

- Sarah was provided with financial/budgeting advice. This included an arrangement to clear the rent arrears and other outstanding bills
- The home care worker's visits were reinstated to help with cleaning, shopping and personal care
- Support was provided to Wayne from various agencies specialising in providing services to 11-17 year olds. This included activities for Sarah and Wayne to re-build their relationship and work with Wayne to gain his support to help with household chores, agree boundaries regarding his use of the property and to help him understand the implications of his behaviour.
- Careers advice was provided to Wayne and to support school attendance.
- A mutual exchange to a two-bed property, which was more suitable for their needs, was facilitated.

What are the key points of good practice and learning from this case example?

- **Changes in circumstances can result in self-neglect and hoarding.** It is important to check whether or not someone new has appeared on the scene and what their impact might be.
- **A comprehensive intervention, involving health services, housing, children's services and adult social services, was used.** No single agency will have all the answers or access to all the resources that might help. Positive outcomes were obtained through meeting Sarah's health, social care and tenancy needs as well as Wayne's education, social and tenancy needs.
- **The one-off deep clean was effective in this situation since it was part of a more comprehensive intervention** and because the clutter and mess was caused by the particular circumstances in which Sarah had found herself. One-off deep cleans are less effective when hoarding is a part of someone's lifestyle.

Sometimes important information only becomes available when further enquiries are made, as in the case of Zoe.

Zoe: drug use, health risks and risk to tenancy

Zoe was 43 years old and had never before come to the attention of adult social services. A specialist practice nurse at the GP surgery raised a safeguarding concern that Zoe faced serious harm or even death due to the severity of her leg ulcers and a carbuncle on her hip. Zoe attended the surgery weekly for treatment but was refusing hospital admission.

Zoe's mobility had declined as a result and the nurse thought that she needed care and support. The GP surgery was the only currently involved party and had concluded that Zoe had the mental capacity to understand the risks to her health by not accepting a hospital admission.

A Multi-Agency Risk Management meeting held which was attended by:

- Zoe's GP
- Practice nurse
- Zoe's mother
- Drug and Alcohol Services
- Police
- Social Services
- Housing
- Zoe was invited but did not attend.

The meeting highlighted some important information

- Zoe was a daily injecting user of heroin and cocaine and her life seemed to revolve around this and her concerns about a debt that she needed to repay.
- Housing confirmed that they had not received complaints from her neighbours but that she lived in an area of high tolerance.
- Zoe's mother raised concerns regarding the security of the property with the door being broken and windows regularly broken. The lights did not work and the smoke alarm beeped continuously.
- The police confirmed that they had carried out welfare visits and that on arrival they had seen people leaving via the back of the property. It was not clear whether or not Zoe was involved in prostitution to earn money or whether these people were fellow drug users.

The following actions were carried out:

- A plan was developed to try and admit Zoe to hospital through encouragement from the practice nurse, mother and GP. The GP liaised with the hospital to ensure a smooth admission.
- If Zoe was admitted, then her mother agreed to clear Zoe's property and housing agreed to prioritise securing the property which may enable Zoe to feel able to go to hospital.
- It was agreed that progress would be reviewed within three weeks.

Zoe was admitted to hospital within the three week review period. As a result, the review meeting was held at the hospital but Zoe did not attend.

During her stay in hospital, concerns were raised about whether Zoe was experiencing symptoms of psychosis. Zoe agreed to have a Mental Health Assessment and when she returned home a Community Psychiatric Nurse and a social worker began to work with her and look at her needs holistically.

The Drug and Alcohol service worked with Zoe who to agree to be prescribed methadone (although she continued to use other drugs). This allowed greater monitoring and less need to secure finances to buy other drugs, although the need remained. Zoe's admission enabled her mother to clear the property and the tenancy sustainment team became involved. Together they made Zoe's home more secure and fixed the wiring.

Zoe's attendance at the GP surgery increased to twice per week for leg dressing and Zoe became more compliant with the compression wraps which are required for treating her ulcers. Zoe accepted sporadic welfare checks by the police, although recognising that these could place her at risk within her community.

The support for Zoe continues and Multi-Agency Risk Management meetings still take place. Zoe will be assessed under the Care Act and she may receive additional support. Zoe also highlighted her wish to have a mobility scooter, which will increase her freedom and independence as she relies on others to help her leave her home.

The risk of harm remains high due to drug use and the people she associates with, but Zoe is now engaging with multiple agencies.

What are the key points of good practice and learning from this case example?

- **Self-neglect may have many causes.** Zoe's self-neglect resulted from her addictive use of drugs. Intervening in this was the most effective way of reducing the harm from her neglect of herself.
- **Hospital admissions can be an opportunity for interventions.** Hospital admissions represent a transition point. Old routines are temporarily broken and the impetus for change can be at its greatest. The person you are trying to help is in a caring environment and there are others there to help them. In Zoe's case, an admission was planned but in other cases it may be unplanned. New things could be learned about Zoe (for example that she may have some psychotic symptoms) and new services could be offered to her.
- **Sometime long-term involvement is required.** The learning about and working with Zoe how best to meet her needs is still on-going and the risk of harm is still high. Quick solutions are not often possible.

Self-neglect and hoarding can be symptoms of other problems as the case of Jack and Joyce illustrates.

Jack and Joyce: hoarding, coercive control and concerns about domestic violence and abuse

Jack and Joyce are 60 years old and live together in a 4 bedroomed semi-detached house, which they own. They have been married for over 30 years and have no children.

The Local Authority first became aware of Jack and Joyce following Joyce's admission to hospital. Upon discharge home, Joyce was visited by an occupational therapist and a physiotherapist who reported that the house was very cluttered and hoarded with newspapers. Local Fire Service Officers visited to carry out a home fire safety visit. They could not gain access to some of the rooms due to the amount of clutter. They found that there were no safe exit routes and concluded that the property posed considerable fire risk.

Due to the severity of the hoarding it was impossible to access the dining room, two of the bedrooms and the upstairs bathroom. The downstairs toilet was in poor condition, had no door and required unblocking on a daily basis. This room and the kitchen in particular were extremely unhygienic. The kitchen is severely hoarded and there is food and empty alcohol

bottles on the surfaces and the floor. Joyce is unable to access the kitchen due to the hoarding and therefore is unable to use this as a fire exit. Joyce said that Jack placed boxes in front of the front door which would prevent her from leaving the property in an emergency.

The walkways throughout the home and up the stairs were narrow and cluttered, with boxes piled on top of other boxes. This was of particular concern as Joyce often holds on to items for stability and these would sometimes topple on to her top forcing her to the floor.

There had been no hot water or heating in the property for over four years. As the main bathroom could not be accessed there is no access to showering or bathing facilities. Joyce has a commode in her bedroom which she is able to use however this has to be emptied downstairs as again there is no access the bathroom. This posed a significant risk to Jack when carrying this down the stairs to empty in the downstairs toilet.

Jack was advised to clear books and newspapers. Further visits were met with resistance by Jack, who declined any support to reduce the level of clutter. The Fire Service concluded that it was highly unlikely that Jack would be able to carry out the necessary work to make the property safe on his own but refused to be helped to do it.

The Fire Service alerted Adult Social Services of these concerns.

Assessment and interventions

Attempts by adult social services to engage with Jack and Joyce were also met with opposition. Persistence and flexibility in visiting and telephoning Jack and Joyce and in liaison and information sharing with other agencies such as the police and health services, enabled a more complete picture of the situation to be developed.

- Joyce depended on Jack to support her (she had a number of health problems including osteoarthritis, epilepsy and depression). Joyce's mobility was poor and she spent an increasing amount of time upstairs in bed.
- Jack was Joyce's main carer but inconsistently and unreliably prepared meals, undertook household tasks and did the shopping
- Jack had a history of mental health problems and at one time had attempted suicide. He had not been in contact with mental health services for over 10 years.
- Their house was in an increasingly poor condition. Despite claims that he would do so, Jack did not fix the central heating or the plumbing problems or clear away the clutter.
- Over the previous two years there had been seven reports of assaults on Joyce by Jack or threats to kill her. Despite this, Joyce had refused to press charges.
- There was evidence of coercion and control. Joyce disclosed that Jack had taken the house keys from her, kept telling her that he was going to send her away and repeatedly ignored her sometimes for days at a time. Joyce said that Jack would not allow her to go downstairs if she was not dressed and that he would not support her to get dressed. Joyce wanted to receive support but Jack would not let anyone else into the house.
- There was evidence of neglect. Joyce was in bed in an unheated bedroom (often with the windows open too), her commode was not emptied, Jack controlled her use of an inhaler for asthma and on several occasions, Joyce had not eaten for over 40 hours at a time.

- All of this was having a negative impact upon Joyce's health. She was very pale, had a chesty cough. There was a growing concern that Joyce would deteriorate further and that she may not recover.
- Joyce was scared of being alone and said that she could not leave her husband due to her religious beliefs. Joyce wished to remain at home but to be in a safe environment.

Intervention

Whilst initially, there had been no doubts about Joyce's mental capacity to make decisions regarding her care, support and decisions regarding where she lived, it became apparent that that she was being coercively controlled by Jack.

The Local Authority concluded that Joyce was not getting the necessary care and support from Jack and began to prepare a case to take to the Court of Protection. Jack was notified of this.

Jack then started engaging with services in order to stop court proceedings. Over the past three months Jack allowed weekly visits from a specialist hoarding support service. Joyce began to receive two care calls per day ensuring that the commode was emptied and that her medication was safely managed. Jack was offered support with depression and feelings of anger through his GP. Jack and Joyce continue to be offered on-going support and the aim is now to repair the central heating when all of the rooms have been cleared and can be accessed.

What are the key points of good practice and learning from this case example?

- **Domestic Violence and Abuse and coercive and controlling behaviour.** Joyce was in a complex co-dependent relationship with her husband Jack. Physical violence and emotional abuse and control had become part of their relationship but Joyce had been unwilling to press charges and could not otherwise seek help. Instead of just accepting this, the workers in the case recognised that something needed to be done. They realised that Joyce's mental capacity to make decisions about her care was compromised by her relationship with Jack and that this could be taken to the Court of Protection.
- **Use of the law.** The decision to go to Court was based on the Article 2 of the European Convention on Human Rights duty to preserve Joyce's life. In this case the threat of legal action was sufficient to create an opportunity for change. Sometimes coercive action is needed to break impasses and to overcome barriers. It is important that this is done sensitively, that notice is given, there is an opportunity to avoid it and support is made available.
- **Mental health problems.** Jack had a history of mental health problems and these may have affected his ability to support Joyce. In these complex situations interventions that support both people are likely to be more effective than those that just focus on one person.
- **Use of a specialist hoarding agency.** The use of experts who can work intensively with people who hoard to help them to declutter can be very effective.

7 Good practice for working with people who self-neglect and or hoard

The following is a summary of key points, many of which were identified in the case studies, to bear in mind when working with people who self-neglect and/ or hoard. These are taken from published research and from practice experience. Remember to read your organisations' policy, procedure or protocol for working with people who self-neglect and/ or hoard since it will contain a lot of useful information.

If you are a supervisor or manager, the following will also be useful when supporting social workers in their work and will offer areas for exploration when barriers and challenges have made work difficult.

Assessment

Good assessment is an essential component of effective working and good risk assessments and mental capacity assessments are particularly important for people who self-neglect and/ or hoard:

- Risk assessments need to be:
 - Holistic and include fire risk, use of emollient creams, smoking, self-harm and suicide, risk to others etc.
 - Based on evidence and not just the person's self-reports.
 - Updated regularly as circumstances change.
 - Use already existing procedures and protocols for escalation if the situation deteriorates to become dangerous
 - Recorded accurately, clearly and to include likelihood and significance/ impact for each risk.
 - Responsive to repeating patterns (not just considering each referral or concern in isolation)
- Mental Capacity assessments need to:
 - Be robust and clearly record which decisions someone is assessed as having or not having the capacity to make, and the person's ability to use and weigh information.
 - Be used when working with long term users of drugs and alcohol and with related brain injury.
 - Identify when people are in conflicted relationships and find decisions hard to make.

Multi-agency working

No one has all the answers. Therefore:

- Draw on the expertise of others.
- Share information and concerns quickly.
- Work through problems together. Involve GPs
- Involve family members and others who might help

Key principles:

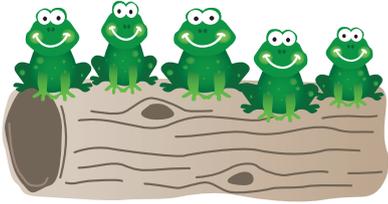
- Identify desired outcomes from risk assessments.
- Persistently offer support, have “professional curiosity” and follow people up.
- Build rapport and trust.
- Explore lifestyle choices.
- Understand the meaning and significance of self-neglect.
- Work patiently but use moments of motivation to make changes.
- Keep questions of mental capacity in mind about self-care decisions.
- Communicate about options especially where coercive action is a possibility.
- Root interventions in legal powers and duties.
- Think flexibly about how family members and others in the community can help.
- Coordinate agency actions and make the most of professional expertise.
- Make sure that all interventions have a purpose and that expected outcomes are followed through and their effectiveness is measured and used to determine the next steps.
- Involve the person at risk and identify their desired outcomes.
- Identify and use transition points i.e. discharge from hospital, change of service provider etc.

Implementation

What is the best approach to take? There is no “one size fits all” approach that will work each time. Here are some things to consider:

- When will a s42 enquiry be the best approach and when will a multi-agency risk management approach be most useful? What approach will have the most positive impact?
- How do you maintain the principles of Making Safeguarding Personal and of well-being? Remember that involving the person who self-neglects and/ or hoards is more likely to foster a better and more constructive relationship with them and be more effective.
- Is there a need to raise the concerns with senior colleagues both within and outside your organisation to overcome obstacles or inaction? Working with people who self-neglect is difficult and sometimes agencies conclude that there is nothing that they can do and then collude together to maintain, rather than to challenge, this. Are there already established escalation mechanisms such as risk panels that can be used to do this?
- When should you use person-centred and relationship-based approaches or a more assertive approach? What are the risks and how serious are they? Is a protective and assertive intervention needed now to preserve life or is there time to develop a relationship?
- Is there a need to balance the person’s autonomy and the right to self-determination with our duty of care?
- In some circumstances, particularly those involving relationships, it can be concluded that whilst a person may not lack mental capacity they are under duress and therefore are disabled from making a free choice. Consequently, the inherent jurisdiction of the High Court may be used to authorise interventions to restrict liberty in the short term in order to protect it in the longer term.
- Is there a need to be directive and to respectfully challenge the person who self neglects about what the risks are and what might happen to them? This needs to be balanced with the requirements under the Mental Capacity Act to not use excessive persuasion or undue pressure when supporting someone who may lack capacity and to not treat someone as lacking capacity if they make unwise decisions. The key thing is to keep involved and to maintain contact with people who make unwise decisions. People do change their minds.
- How trauma informed is practice? Has the work been sensitive and aware of the impact of adverse experiences upon people who self-neglect and hoard? Has this been used to refine and direct interventions?
- Is there a need to use the law, including non-social services legislation and the Mental Health Act?
- Are you following the available guidance in your area?
- Are decisions recorded and defensible if you have to explain them in court?

8 And finally...



“Five frogs are sitting on a log. One decides to jump off. How many frogs are now sitting on the log?”

The answer is “five”.

Making a decision is not the same as acting upon it.

Other resources

Organisational guidance

Make sure you familiar with the guidance already provided by the organisation that you work for. It will often include useful local information and contacts too. Examples are:

<http://www.safeguardingcambspeterborough.org.uk/adults-board/information-for-professionals/cpsabprocedures/multi-agency-risk-management-guidance/>

<http://www.safeguardingcambspeterborough.org.uk/adults-board/information-for-professionals/cpsabprocedures/hoarding/>

<http://www.safeguardingpeterborough.org.uk/adults-board/information-for-professionals/selfneglect/>

<https://www.norfolksafeguardingadultsboard.info/professionals/self-neglect-and-hoarding/>

<https://www.essexsab.org.uk/types-of-abuse/neglect-self-neglect>

<https://www.thurrocksab.org.uk/preventing-abuse/types-of-abuse/self-neglect>

Other guidance

There are a number of reports and guides available that report on research and summarise the experience of practitioners who work with people who self-neglect and/or hoard. Examples include:

<https://www.scie.org.uk/self-neglect/at-a-glance>

<https://www.scie.org.uk/files/self-neglect/policy-practice/report69.pdf>

<https://www.housinglin.org.uk/Topics/type/Hoarding-of-Housing-The-intergenerational-crisis-in-the-housing-market/>

https://www.thinklocalactpersonal.org.uk/_assets/MakingItReal/TLAP-Making-it-Real-report.pdf

Further reading

Vile Bodies: Understanding the neglect of personal hygiene in a sterile society
by Peter Bates

Self-neglect article: *Tension between human rights and duty of care*
(Community Care inform)

A Guide to working with adults who hoard (Community Care inform)

National Housing Association: *Hoarding: Key considerations and examples of best practice*

Hoarding and how to approach it – guidance for Environmental Health Officers and others
Chartered Institute for Environmental Health

Buried in Treasures: Help for compulsive acquiring, saving and hoarding
by Randy Frost and Gail Steketee (2014), 2nd Edition

Overcoming Hoarding: A self-help guide using cognitive-behavioural techniques
by Satwant Singh, Margaret Hooper, and Colin Jones (2015)

Braye, S., Orr, D. and Preston-Shoot, M. (2011) *Self-Neglect and Adult Safeguarding: Findings from Research*. London: SCIE

Braye, S., Orr, D. and Preston-Shoot, M. (2013) *A Scoping Study of Workforce Development for Self-Neglect*. London: Skills for Care

Braye, S., Orr, D. and Preston-Shoot, M. (2014) *Self-Neglect Policy & Practice: Building an Evidence Base for Adult Social Care*. London: SCIE

Relevant legislation

The following are examples of relevant legislation that may be useful when working with people who self-neglect and/ hoard.

The Care Act (2014) statutory guidance – self-neglect is included as a category under adult safeguarding.

Article 8 of the Human Rights Act 1998 gives us a right to respect for private and family life. However, this is not an absolute right and there may be justification to override it, for example, protection of health, prevention of crime, protection of the rights and freedoms of others.

Mental Health Act (2007) s.135 – if a person is believed to have a mental disorder and they are living alone and unable to care for themselves, a magistrate's court can authorise entry to remove them to a place of safety.

Mental Capacity Act (2005) s.16(2)(a) – the Court of Protection has the power to make an order regarding a decision on behalf of an individual. The court's decision about the welfare of an individual who is self-neglecting may include allowing access to assess capacity.

Public Health Act (1984) s.31-32 – local authority environmental health could use powers to clean and disinfect premises but only for the prevention of infectious diseases.

The Housing Act (1988) – a landlord may have grounds to evict a tenant due to breaches of the tenancy agreement.

