



**Merseyside Safeguarding Adults Board**

*In conjunction with*



## **The Short Guide to Working with People in Circumstances of Complex Self-Neglect**

### **Self-Neglect Toolkit**

April 2019

*“As Independent Chair of the Merseyside Safeguarding Adult’s Board I am pleased to introduce this Practice Guide for colleagues of all agencies working with people who self-neglect within the Boards area. I hope you find the Guide helpful, as we have spent the last year developing it with a wide range of colleagues from many different agencies and consulting with people who self-neglect, to make sure that it is relevant and useful in your day to day work.*

*Responding to self-neglect can be a complex and difficult area of your work, and there has been a range of academic interest in the causes of, and outcomes for, people who self-neglect. But what I have been encouraged by is some of the very practical suggestions within this Guide, as well as the shared sense of purpose by a wide variety of agencies to try to engage and improve the wellbeing of people who self-neglect.*

*I have also been impressed by the way in which colleagues from the different agencies involved in the development of this Guide, have recognised that the challenges they experience individually in working with people who self-neglect, are shared across all agencies, and that it is only by working together in partnership that we can really make a difference.*

*I know that one of the challenges of working with people who self-neglect can be your own agencies processes, as understandably resources and time can be limited by the demands placed on each of your organisations, but I hope that this Guide gives you confirmation that you are not alone, and gives you confidence in conversations with your colleagues and managers about what helps when you are trying to engage with someone who self-neglects.*

*In developing this Guide, I was mindful that the Safeguarding Adult Board has a responsibility to prevent abuse and neglect in its area and to understand the experiences of staff working with people who self-neglect, and while I acknowledge that each of your organisations will have its own procedures and processes, it is an expectation that these will be compatible with this Guide”.*

*Sue Redmond  
April 2019*

# The Short Guide to Working with People in Circumstances of Complex Self-Neglect

## Who is it for?

For all professionals working in complex self-neglect situations.

## What is it designed to do?

- To help you make defensible decisions
- To give you suggestions about what you can do in difficult situations, based on the experience and insights of other professionals in Knowsley, Sefton, Liverpool and Wirral, working with people who self-neglect
- To make sure you, and all the other agencies you work with, have tried everything you possibly can
- To help you put together the pieces of the multi-agency puzzle

## With thanks to:

All of the staff from many different agencies, across the four boroughs, who came to the self-neglect workshops held at Liverpool John Moores University during 2018. Discussions and ideas from these workshops led to this short guide being compiled.

The Hoarders Helping Hoarders Peer Support Group who read, commented on, and made additions to this guide.



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Useful things to remember when working with people in complex cases of self-neglect

**Show curiosity, interest and concern about people's welfare.**

*Relationship building is crucial. Be patient and work at their pace.*

**Find out what the person wants and expects, and what is worrying them, see if they feel able to cope or resolve some things for themselves.**

*Identify whether any risks (or worries) require immediate action – what is the duration and seriousness of the self-neglect. Are the problems low, medium or high risk?*

**Try to understand the history of how they came to be self-neglecting, and their worldview – what is their life like? Consider trauma, bereavement, loss, divorce. Be aware of any diversity issues.**

*At the right point be open and honest with the person (particularly about what your worries are about them). Reinforce the positive aspects of their life.*

**Identify the supports that might be out there for them.**

*Offer choices, but don't make promises you can't keep, don't over-promise.*

**Call a case conference or professionals meeting early on in the process. Share the risk.**

*Everyone (including you manager) needs to understand that persistence and commitment require time.*

**Work on shared goals, not goals based on how you think they should live.**

*Proportionality is everything. Don't use a sledgehammer to crack a nut.*

**Persist, don't give up, keep going back, but make sure your involvement is lawful.**

*Liaise with other professionals, and where possible the adults family and friends, give thought to who else could usefully be involved.*

**Negotiate 'quick wins' for the person – possibly leading to 'bargaining'.**

*Remember human rights!*

**The term 'self-neglect' can be perceived as a very stigmatising and emotive term – be careful how you use it.**

## Myth busting about self-neglect and what agencies can do

**Myth:** We (social worker, nurse, psychologist, occupational therapist, mental health team etc) can wave a magic wand

**Myth:** Medication and therapy can provide a quick solution

**Myth:** Safeguarding will sort everything out ('an easy referral can make this person safe')

**Myth:** If a safeguarding referral is made, the social worker can enter a person's home and remove self-neglecting people from their property

**Myth:** People can be forced to engage in person care task and have support from care agencies. Staff can 'just do it' for the person to fix the problem

**Myth:** If a person refuses help, such as with de-cluttering of clearing we can force them to accept it

**Myth:** Social workers can over-ride someone's decision when they have capacity

**Myth:** Social workers have powers of surveillance

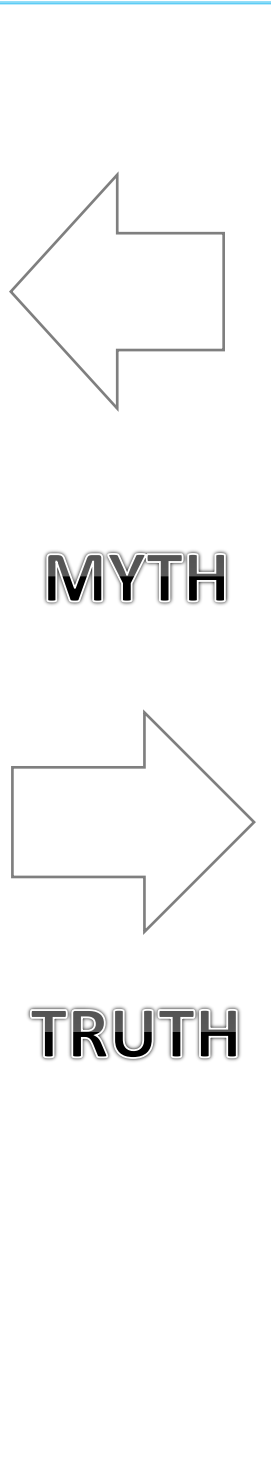
**Myth:** Only doctors can assess mental capacity

**Myth:** Patients cannot be discharged from hospital if their property is not in a good State

**Myth:** If we clean the house out, the problem will be sorted

**Myth:** Self-neglecting people are lazy and it's a 'lifestyle choice'

**Myth:** Self-neglect is about hoarders



**Truth:** We can help but the person needs to engage with what is offered

**Truth:** Improving well-being, quality of life or neglectful behaviour can take a long time

**Truth:** It's a team effort. It requires a multi-agency approach to work with complex cases

**Truth:** Social workers are unable to remove someone from their property without consent or a court order or legally prescribed process

**Truth:** A person has to consent to personal care being undertaken. If someone has capacity they have the right to make unwise decisions

**Truth:** It is all about negotiation and understanding why they are saying no, and an attempt to reach a shared goal so some support can be delivered and the risk reduced.

**Truth:** They can't nobody can

**Truth:** They don't

**Truth:** A range of people can assess capacity, depending on how well they know the person and what the decision is that needs to be made

**Truth:** They can

**Truth:** The behaviour probably won't change

**Truth:** Situations can be very complex, and it may be choice in some elements of the adult situation but not necessarily all

**Truth:** Self neglect includes lots of other factors – such as not managing personal care or medication, not paying bills or eating property. Many people who hoard don't self-neglect at all

## What can different agencies do for people who self-neglect?

**Clinical psychologists** can support people who self-neglect by developing a psychological understanding of their situation and helping them to find strategies to help manage their situation, including psychological therapy

**Community nurses** provide healthcare to people in their own homes. They will refer to other services, such as the Continence Service, or for specialist equipment like hospital-type beds.

**Environmental Health** aim to reduce the risk to the self-neglecting person themselves but also to the community, through practical direct work with the person, invoking relevant legislation where necessary.

**Fire & Rescue Services** can provide fire safety advice and put practical measures in place to reduce the risk of a fire. They may refer on to other agencies for more support.

**General Practitioners (GPs)** can identify people who seem to be self-neglecting, provide support and refer to other agencies to enable people to get support and help if required and consented to.

**Hospital nurses** will identify patients who seem to be self-neglecting, support the patient and refer to other agencies to enable patients to gain help and support if required and consented to whilst in hospital.

**Housing staff** can help people very practically to support their tenancies if they are at risk of being evicted because of problems with self-neglect or hoarding.

**Independent Advocates** support the person to make their own decisions, ensures their views, wishes, feelings, beliefs and values are listened to, and may challenge decisions that they feel are not in the person's best interests.

**Occupational therapists** work with individuals to identify any difficulties they experience in day to day living activities, and finding ways to alter or solve them. They support independence where possible and safety within the community, and build confidence and motivation.

**Paramedics** are called by the patient or a third party caller due to medical concerns or health deterioration. They will deliver appropriate emergency treatment, assess mental capacity in relation to the health issues presented (particularly if a person is refusing to go to hospital), and refer on to other agencies with concerns.

**Physiotherapists** can help with treatment of injury, disease and disorders through physical methods. A physio helps and guides patients, prescribes treatment and orders equipment.

**Police** can investigate and prosecute if there is a risk of wilful neglect, they can provide safeguarding to families and communities by sharing information, refer to specialist partner agencies, and use force to gain entry/access if there are legal grounds to do so. The PCSO Early Help Team will refer to other agencies and signpost.

**Probation case managers** will identify problems via home visits and provide regular monitoring. They may refer on to social services, mental health services, housing, health etc. They will complete risk assessments and risk management plans, making links to the risk of serious harm.

**RSPCA** investigate complaints of cruelty and neglect to animals and offer support and advice.

**Social workers** will complete an assessment by taking to and getting to know the person. They may establish their mental capacity to make particular decisions about their lives, look at all of the options. They may put in a package of care, or refer to other agencies for the services that they provide (for example, to fire services for a fire safety check). They might arrange multi-agency meetings to discuss concerns and ways forward. They can help with relationship building and communication skills, and try to develop support networks.

**Voluntary, Community and Faith Sector (VCFS)** staff and volunteers can provide a whole range of social opportunities and support services that can connect people with their communities, e.g. luncheon clubs, support groups. Health advice, furniture recycling, food banks, advocacy etc. Staff and volunteers can be a key part of formal as well as informal plans and support.

**What professionals think an adult who self-neglects might hope (and fear) when they arrive in their lives:**





## The Mental Capacity Act 2005 – 11 things to think about

A person MUST satisfy the two-stage diagnostic test before you can make a decision about their capacity. So they must have an impairment of the mind or brain, and it must be enough of an impairment to mean that they can't make a particular decision at this particular time. If they haven't got impairment, then why are you testing their capacity?

Just because someone has an impairment, doesn't mean they lack capacity!

You need to be really clear about what the specific decision is that needs to be made. You must establish what the decision is that the person needs to make, so that you can confidently say 'this person does or doesn't have capacity to make this particular decision at this particular time'.

People who do have capacity may still need support. They may still be living in a desperate, risky, unhappy situation that we could try to help do something about, and we still have a duty of care.

Refusal of treatment does not necessarily indicate a lack of capacity

Indecision or avoidance should not be confused with lack of capacity

It's always ok to get a second opinion, and have someone else in the room

Good recording is essential, particularly in the case of 'unwise or eccentric' decisions

People have a right to make 'unwise decisions'. If it's a significant change from their usual opinions or previously stated wishes you might want to clarify things, but in itself it doesn't mean they have not got the relevant mental capacity.

You must be satisfied that you have fully discussed the risks in a situation, so that the person has the information they need to understand, retain, and use and weigh information about their situation. Otherwise, how can you possibly know that the person has really thought about all of the information that is pertinent to the decision to be made?

On the other hand, if a person lacks capacity, it's not a 'done deal'. It doesn't mean they can be spirited off to a residential home, for example. You have to have a very, very good, legally sanctioned reason for removing a person from their home. If a person lacks capacity then the least restrictive option should be the first to be considered

## Executive and decisional capacity – think about whether this is worth exploring further with people who self-neglect

Mental capacity involves not only the ability to *understand* the consequences of a decision, (decisional capacity), but also the ability to *execute*, or carry out, the decision, (executive capacity).

A simple way to demonstrate this is to use ‘tell me/show me’ approaches. Ask the person to ‘tell you’ how they do something, and then ask them to ‘show you’ how they do it.

### Here are some suggestions from practitioners about how this could be done

- You need to observe the person’s practical ability to complete actions relating to a decision such as cleaning, shopping or cooking. For example, a person may say they are able to make meals, no problem, but you can’t see any evidence that meals are being prepared or cooking done. You could ask them to show you how they make a cup of tea, or a slice of toast.
- Sometimes, people have physical difficulties with completing an action. For example, a person may say they are able to take their medication independently. But when you look at the medication blister pack it is unopened. It may simply be that the person is unable to open the blister pack unassisted.
- A person may have the ability to self-medicate, but make the decision not to take the necessary medication as they fear the side effects (such as frequent urination), or they lack confidence in its efficacy.
- It may be hard to separate out embarrassment, avoidance, or the person just changing their mind from ‘decisional incapacity’ as they can be almost identical in how they present. People who self-neglect may have compounding factors.
- In hoarding situations, a person may have the ability to clean up or order a skip, but that doesn’t take into account the related emotions – the value of their possessions to them, emotional significance of the items, safety, anxiety or guilt.
- Decisional and executive capacity may be difficult to test in some environments, such as hospital. ‘Testing’ decisional capacity may require there to be a level of trust that comes from a more established relationship.

## 'Have you tried?' Common practice situations

**Neighbours have raised concerns about Mr W – but he won't let anybody in.**

### **Have you tried?**

#### **Before you go out, think about:**

- Are you the 'preferred professional' for this person? If not, who is?
- Is it necessary to meet at home? Where else do they go? Can you meet them outside the home in a neutral non-threatening place – GP surgery? Café? Pub?
- Would they like to bring a friend or have a friend present when you visit?
- Can a family member or neighbour introduce you?
- Texting people directly in advance of your visit to re-assure them
- Agreeing a 'secret knock' with the person if they are concerned about letting people in
- Be discrete, because the person doesn't want to lose face with their neighbours
- Joint visits with referrer or someone they trust (e.g. CPN if they are known)
- Think about what other services are likely to have contact with the person, such as the Fire service, Housing, utility companies. Can you do a joint visit?
- Can you enlist the help of faith, voluntary and support services, Church leaders etc
- Can you make an appointment, by phone or letter, rather than just turning up?
- Can you build rapport before the visit on the phone?
- If the person is known, use your previous experience? What has worked or failed before?

#### **When you go out:**

- Plan what you are going to say ahead of time
- Don't wear a uniform if at all possible
- Don't go 'suited and booted', in masks etc - need to build rapport before that
- Consider what can be offered to make things better?
- Be open and honest about why you are there.
- Be informal
- Getting in does not necessarily mean getting on - engage, engage, engage
- Do not be oppressive and forceful
- Are there little opportunist things you can make the most of? Offer to buy milk!
- Approach from a positive not a critical angle
- Be conscious of your body language and compromise yourself sometimes, so you don't make people feel uncomfortable

#### **If you fail to get in:**

- Revisit all of the points above
- Be persistent
- Try cold calling
- Put a note through the letterbox, giving another time when you will call back
- Put a note through the letterbox asking Mr W to phone you
- Use predictable crisis events
- Contact police if the person has not been seen for some time, or if there are any concerns.

**Finally, Mr W has let you in, but is very uncommunicative and suspicious**

**Have you tried?**

**Introduction (the first 5 minutes is very important)**

- Asking Mr W to show you how he does things around the house
- Starting with safe conversations using visual clues– look at family photos, ask about hobbies, what are you having for tea, etc
- Trying to not show your opinions or being judgemental
- Looking for positive avenues and topics of conversation and developing them
- Trying to find a common interest
- Don't try to get things done, do nothing, just chat ...can be very different from normal visits
- Don't make promises you can't keep, be honest, right from the start

**The assessment**

- Identifying a health/care need and possible solutions which Mr W is agreeable to
- Asking if you can contact family/carers
- Checking entitlements and other services/agencies available
- Offering good choices.
- Creating outcome focussed assessments with Mr W
- Setting realistic SMART goals
- Focussing on risks rather than telling Mr W how to live.
- Thinking about the consequences of risks and be honest
- Making sure the action plan and reviews are created by Mr W
- Working with him, not doing it to him
- Trying a staged approach, not doing everything at once
- Celebrating successes
- Thinking about your verbal and non-verbal approach, be an active listener

**Practical support**

- Offering support on a trial basis
- Considering any other sources of help such as family members
- Are there any immediate agreed actions (quick wins?)
- Working with Mr W to establish his priorities in terms of needs
- Always try to have another option
- Going at the person's pace when supporting them to move or remove items, otherwise it may feel chaotic to the person.
- If you are going to offer a skip (the dreaded 'S' word'), is it because all the items are broken? Can some be recycled instead?
- Just because someone has a lot of items doesn't mean they are unhygienic
- Remembering that the meaning attached to items is logical to the individual
- It's okay to dangle carrots when you've considered different approaches.
- Educate ... health, safety, support
- Emphasising the positives
- Persuading managers to waive individuals' financial contributions, if this appears to be the main obstacle to ongoing intervention
- Looking for support groups and peer support

## Best Practice with people who self-neglect and don't want to engage with services

**Find out if the adult may be in need of care and support and offer assessment, and if eligible, provide care and support services; If they refuse to engage then;**

**Complete a mental capacity assessment if you can, which should be time and decision specific**  
If the adult refuses to engage, gather as much information as possible to inform decision

**Complete a risk assessment, ideally with the adult if you can**  
If the adult refuses to engage, gather as much information as possible to inform the assessment and decision making, then;

**Consider whether there is any legal basis to intervene further. At this point you may need to seek advice**

**It may be reasonable not to intervene further, as long as no-one else is at risk, and the adults 'vital interests' are not compromised (immediate risk of death or serious harm, or whether a crime has been committed, or evidence of coercion)**

**There needs to be clear, documented attempts to discuss this with the adult in order to make sure that all decisions are fully explained and recorded, and support them to:**

- Weigh up the risks and benefits of different options
- Be aware of the level of risk and possible outcomes
- Agree on the level of risk they are taking (including their capacity to take that risk)
- Offer advocacy or other appropriate support

**If the adult continues to refuse to engage, and there are still worries, then;**

Record your reasons for not intervening or sharing information, including every detail of your assessment of the person's capacity and of your conversations with them about the potential risks posed by their chosen action

Review the situation regularly  
Communicate (ideally in writing if appropriate) with them, making sure that they understand where they can go if they want to seek help in the future

**Make sure that other agencies have been informed and involved as necessary**

This means that after all reasonable and proportionate attempts to engage are exhausted, and other agencies have been informed or are involved with the adult, then the case may be closed.

Where there are no other agencies involved at the point of case closure, and the adult will be without any contact, it may be appropriate to discuss with senior management and consider regular contact with the individual via professional support, review or a care and support package. The frequency and duration should be proportionate to the known presenting risks.

## When to keep the person's case open....

Working with people who self-neglect, and building up a trusting relationship with them, can be a very slow, painstaking process. Consistency in terms of the worker who is involved and their approach to the adult is also very important. Practitioners taking part in our self-neglect workshops have told us that this sometimes doesn't sit well with timescales for closing cases and ending involvement.

For social workers especially, there can be pressure to close self-neglect cases, particularly if a service user is refusing to engage, and is deemed to have mental capacity. Yet often substantial worries remain about the self-neglecting person.

**Merseyside Safeguarding Adult Board partner authorities have therefore agreed that in particular high-risk, complex self-neglect cases, involvement should continue and cases remain open.** It is anticipated that the decision to keep a case open longer term than usual, will only apply to a small number of situations, and these will need to be monitored to make sure there are clear aims to continued involvement, rather than the case simply 'drifting' along.

It is really important to think about who is the best person to maintain direct involvement over a period of time, as this may not necessarily be a social worker. It may be a CMHN, a tenancy support worker from Housing, or an occupational therapist for example.

The following ideas will, we hope, help all partner agencies to make decisions about keeping cases open in the longer term.

### Points to consider when deciding whether to keep a complex self-neglect case open to a worker

Every circumstance where an adult self-neglects is unique so there is not a formula in order to arrive at the 'right answer', but we think that there are eight key areas to consider.

We hope the ideas which follow will be a useful tool to use in supervision discussions for example and in assessments of when a case should remain open.

In making the decision for a case to remain open and active, you should consider:

#### 1. The quality of information as to the circumstances

- The adults story and history – what have been major events in their lives, how have they been shaped by these and coped with them, what is important to them?
- Reliability and availability of information
- Existence of care and support needs
- Any changes to presentation, behaviour or routine
- The presence or absence of coercion
- Any previous family, community, housing or safeguarding concerns
- Awareness of the strength, availability and responsiveness of the adult's personal and local networks



#### 2. The risks to the person, and to others

- Seriousness of the circumstances
- Risk of death or major harm
- The nature and timing of the risk
- Has it changed over time?
- Does the risk affect others, such as neighbours or other tenants?
- Are there any children involved?
- Has a crime been committed against the person?
- Consider your 'proportionality and perspective' about the circumstances.



### 3. The likelihood of the risk actually happening

- Immediate nature of the risk?
- Are all variables being properly weighed?
- Is there any objective or research evidence available?
- Consider the over-influence of the 'protection imperative' ("What's the point of making someone safe if in doing so you just make them miserable?" (Munby, LJ, 2007)
- Are you 'over-egging the risk pudding'?




### 4. The relevance of the Mental Capacity Act

- Consider mental capacity in order to do what? Remember any assessment must be issue and time specific
- If you are considering actions that could have a significant impact on the person, you need to be clear that it is the least restrictive option and necessary and proportionate to the presenting risk
- Have all practicable steps been taken to allow the adult to make the decision?
- Making an unwise decision is not the same as being unable to make a decision
- 'Lacking insight' could be simply be taking a 'different view' to that of professionals
- Have you thought about functional and executive capacity (tell me/show me)?
- Even if the person does not have the relevant mental capacity, their wishes and feelings should be considered and they must carry weight in your decision making



### 5. The efforts that have been made to engage with the self-neglecting person

- Intervening successfully depends on taking time to gain the person's trust and build a relationship, and going at the person's own pace. Have you done that? What evidence have you got that you are progressing?
  - Using the relationship you have with the adult to make it possible for them to look after themselves
  - Encouraging them to continue the conversation with other people who they trust
  - Record your reasons for not intervening
  - Include detail of your assessment of capacity and of your conversations about the potential risks posed by their chosen action
  - All decisions should be fully explained and recorded
  - Other agencies should be informed and involved as necessary
  - Support the adult to weigh up the risks and benefits of different options
  - Review the situation regularly and agree your approach with your manager
  - Test out if the adult understands where they can go if they want to seek help in the future
- 



## 6. The strength of the adults views

- What is the adult's rationale for their views or opinions?
- Is it consistently stated, or has it changed or developed over time?
- Is what they want to happen possible, lawful and does it impact on other people's rights?
- Is it legitimate or reasonable in the circumstances?
- Are they declining all support to help address needs, or just some?
- Can they demonstrate an ability to adapt to other changes in circumstances?
- The adult's rights to privacy and family life *could* outweigh concerns. You must consider the Human Rights Act.
- Different people give different weight to different factors or concerns – the person may simply not see the situation as being as serious as you do.



## 7. The steps necessary to reduce risk

- Would the steps taken to reduce the risk be lawful, necessary and proportionate to the risk?
- Consider the important balance between the adult's rights to life, freedom from inhuman treatment and from discrimination, with their rights to liberty, fairness and privacy
- Is the intervention proportionate to the need to protect from harm or the real possibility of future harm? If not, then without due care our efforts to safeguard a person may in themselves become abusive
- In most cases, a court must decide whether someone should be removed from their home against their wishes. You should not take certain steps without the sanction of the court. Your legal team can advise you further.



## 8. The likelihood of future engagement

- What are the real, known strengths, availability and responsiveness of the adult's support networks? Can they be strengthened or expanded?
- Is there organisational capacity to monitor and review the situation regularly?
- Are you assured that they understand where they can go if they want to seek help in the future?
- What is the best communication method for the person?
- Is there room for compromise, expediency, delay or better timing?
- Could someone else have more likelihood of successfully engaging with the person, and what a good outcome would look like?
- Have other agencies been informed and are they involved as necessary?
- The frequency and duration of any contact and efforts to engage should be proportionate to the factors above.



This guide has been compiled by Elaine Aspinwall-Roberts, from Liverpool John Moore's University and Paul Dalby from Knowsley MBC.

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