ENGAGING AND INTERVENING WITH PEOPLE WHO SELF-NEGLECT: WHAT WORKS?

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What do we mean by self-neglect?

<table>
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<tr>
<th>Neglect of self-care</th>
<th>Neglect of the domestic environment</th>
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<tr>
<td>Personal hygiene</td>
<td>Hoarding: (“persistent difficulty</td>
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<td>discarding or parting with</td>
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<td>possessions, regardless of value”</td>
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<tr>
<td>Nutrition/hydration</td>
<td>DSM V )</td>
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<td>Health</td>
<td>Squalor</td>
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<td>Infestation</td>
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To such an extent as to endanger health, safety and/or wellbeing

Refusal of services that would mitigate risk of harm

“Self-neglect: this covers a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding” (DH 2016)
Care Act 2014: bringing self-neglect in from the cold…

SAB oversight of measures to help and protect

Self-neglect

Safeguarding

Adult social care

Multiagency process
The research evidence

- SAB governance
- Scoping the evidence on self-neglect
- Workforce development needs 2013
- Review of serious case reviews 2014-16
- Exploring self-neglect practice 2013-14
The key challenges of self-neglect: how can the research point ways forward?

- Mental capacity
- Ethical dilemmas
- Understanding
- Legal rules
- Organisational features
- Interagency cooperation
1. Understanding causation: association with

**Physical health issues**
- Impaired physical functioning
- Pain
- Nutritional deficiency

**Mental health issues**
- Depression; negative symptoms
- Frontal lobe dysfunction
- Impaired cognitive functioning

**Substance misuse**
- Alcohol
- Other drugs

**Psycho-social factors**
- Diminished social networks; limited economic resources
- Poor access to social or health services
- Personality traits; traumatic histories/life-changing events; perceived self-efficacy
But …

No one overarching explanatory model

Complex interplay of physical, mental, social, personal and environmental factors

Unwillingness and inability difficult to distinguish

Shifting levels of engagement

Need for understanding the meaning of self-neglect in the context of each individual’s life experience
Understanding the lived experience: neglect of self-care

- **Negative self-image:** demotivation
- **Different standards:** indifference to social appearance
- **Inability to self-care:**

  I got it into my head that I’m unimportant, so it doesn’t matter what I look like or what I smell like.

  I’m drinking, I’m not washing; I wouldn’t say I’m losing the will to live, that’s a bit strong, but I don’t care, I just don’t care.

  “I wouldn’t say I let my standards slip; I didn’t have much standards to start with.”

  (It) makes me tired ... I get tired because daily routines are exhausting me, to do the simple things like get washed, put on clean clothes, wash my hair.

  I always neglected my own feelings for instance, and I didn’t address them, didn’t look at them in fact, I thought ‘no, no, my feelings don’t come into it’.
Understanding the lived experience: neglect of domestic environment

- **Influence of the past:** childhood, loss
- **Positive value of hoarding:** a sense of connection, utility
- **Beyond control:** voices, obsessions

The only way I kept toys was hiding them.

“When I was a little boy, the war had just started; everything had a value to me … everything in my eyes then, and indeed now, has potential use.

I want things that belonged to people so that they have a connection to me.

I don’t have time to make a note of everything in the paper that has an interest to me and so I’m very fearful of throwing something away.

The distress of not collecting is more than the distress of doing it.
Keith’s story

- https://www.youtube.com/watch?v=fhmfptpwNZc

- As you watch the video, think about the multiple influences on Keith’s behaviour, and how they have affected his self-neglect journey
- What has made the difference for him?
2. Ethical dilemmas

- The state's duty to protect from foreseeable harm
- Human dignity compromised
- ECHR articles 2 and 3
- Risk to others
- Professional codes of ethics
- MCA 2005
- ECHR articles 8 and 5
- Limitations to state power
- Policy context of personalisation
- Making safeguarding personal
- Respect for autonomy & self-determination
- Duty to protect and promote dignity
- The state's duty to protect from foreseeable harm
- Human dignity compromised
- ECHR articles 2 and 3
- Risk to others
The tricky concept of lifestyle choice

- SARs tell us that we are quick to assume capacity, respect autonomy (and walk away)
- But life stories tell us otherwise:

- I got it into my head that I’m unimportant, so it doesn’t matter what I look like or what I smell like.

- “Well I don’t know to be honest. Suddenly one day you think, ‘What am I doing here?’ ”

- “I used to wake up in the morning and cry when I saw the sheer overwhelming state... My war experience in Eastern Europe was scary, but nothing compared to what I was experiencing here.”

- Your esteem, everything about you, you lose your way … so now you’re demeaning yourself as the person you knew you were.
Challenging the dichotomy

<table>
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<tr>
<th>Is it really autonomy when ...</th>
<th>Is it really protection when ...</th>
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<tr>
<td>• You don’t see how things could be different</td>
<td>• Imposed solutions don’t recognise the way you make sense of your behaviour</td>
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<tr>
<td>• You don’t think you’re worth anything different</td>
<td>• Your ‘sense of self’ is removed along with the risks: “hoarding is my mind”</td>
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<td>• You didn’t choose to live this way, but adapted gradually to circumstances</td>
<td>• You have no control and no ownership</td>
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<td>• Your mental ill-health makes self-motivation difficult</td>
<td>• Your safety comes at the cost of making you miserable</td>
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<td>• Impairment of executive brain function makes decisions difficult to implement</td>
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A more nuanced ethical literacy

Respect for autonomy entails

- Questioning ‘lifestyle choice’; respectful challenge; care-frontational questions
- Dialogue towards ‘positive autonomy’: maximise capacity to see options and make care-ful choices

Protection entails

- Close attention to wishes, feelings, beliefs and values
- Proportionate risk reduction

“Respecting lifestyle choice isn’t the problem; it’s where people don’t think they’re worth anything different, or they don’t know what the options are.”

Autonomy does not mean abandonment
A relational approach: ethical action situated within relationship

Intervention delivered through relationship: emotional connection/trust

Support that fits with the individual’s own perception of need/utility: practical input

Respectful and honest engagement

She got it into my head that I am important, that I am on this earth for a reason.

He has been human, that’s the word I can use; he has been human.

He’s down to earth, he doesn’t beat around the bush. If there is something wrong he will tell you. If he thinks you need to get this sorted, he will tell you.

With me if you’re too bossy, I will put my feet down and go like a stubborn mule; I will just sit and just fester.

The idea is not to get too pushy about it; people start getting panicky then, you know? ‘You’re interfering in my life,’ that kinda thing.

They all said, ‘we’re not here to condemn you, we’re here to help you’ and I couldn’t believe it. I thought I was going to get an enormous bollocking.

“Tenancy support … weren’t helping … just leaving it for me to do. Whereas when x came, they were sort of hands on: ‘Bumph! We’ve got to do this’ … shall we start cleaning up now?’

She got it into my head that I am important, that I am on this earth for a reason.

With me if you’re too bossy, I will put my feet down and go like a stubborn mule; I will just sit and just fester.
Knowing, Doing and Being

- **Knowing**
- **Doing**
- **Being**

**Professional knowledge; finding the person**

**Hands-off/ hands-on; proportionate risk containment; find the latitude; recognise the impact**

**Relationship**

- Patience, persistence, empathy, compassion, humanity
3. Mental capacity: affects perception of risk and intervention focus

- Mental capacity
  - Respect autonomy
    - Best interests: preventive
  - Self-care
  - Best interests: remedial
    - Self-neglect
  - Mental incapacity

- Mental capacity: affects perception of risk and intervention focus.
Mental capacity: a reminder

- Capacity is **decision specific and time specific**
- A person lacks capacity if (at the time the specific decision has to be made):
  
  - They have an impairment or disturbance in the functioning of the mind or brain, as a result of which they are ...
  
  - Unable to make the decision – unable to understand, retain, use or weigh relevant information, or communicate the decision
Challenges of mental capacity assessment in self-neglect

- Decision-specific and time-specific nature of assessment
- Social, motivational & affective factors affect cognitive processes
- Where do you start? Impairment or processing information?
- How to account for ‘good in theory, poor in practice’ decisions?
Mental capacity in the self-neglect literature

- Involves not only
  - the ability to understand and reason through the elements of a decision in the abstract
  But also
  - the ability to realise when a decision needs to be put into practice and execute it at the appropriate moment – the ‘knowing/doing association’

- Frontal lobe damage may cause loss of executive brain function, resulting in difficulties:
  - understanding, retaining, using and weighing information in the moment, thus affecting
  - problem-solving, enacting a decision at the appropriate point
A more nuanced understanding

Articulate and demonstrate models; the person in context; real world behaviour

GW v A
Local Authority [2014] EWCOP20
Review your experience

• What examples can you share of positive work in self-neglect?
• How did you manage to make a difference?
4. The organisational context

Care management models
- Time limited, set stages
- Closure pending review
Performance management

Thresholds that limit preventive work
Charging policies
Features of the local care market
A perfect storm

“The combination of people who are terrified of losing their independence or terrified of state intervention, together with a state process that is desperate to apply eligibility criteria and find reasons not to support people, is just lethal.... It’s just like: ‘oh you’re saying it’s all fine, thank goodness, we can go away’”.
Organisational support for practice

How it feels
• Self-neglect work feels lonely, helpless, risky & frustrating; practitioners feel exposed and uncertain

Supervision and support
• Recognise personal impact
• Support and challenge
• Advice from specialist

Time for a ‘slow burn’ approach
• Workflow that permits repeat visits and longer-term engagement

Shared risk management & decision-making
• Places & spaces to discuss: panels/forums
5. The complexity of the legal framework

- Care Act 2014
- Mental Health Act 1983
- Mental Capacity Act 2005
- Data Protection Act 1998
- Powers of entry
- MCA 2005 DoL
- Inherent jurisdiction
- Beyond health & social care
Legal literacy

The ability to connect relevant legal rules with the professional priorities and objectives of ethical practice

- Sound knowledge of legal rules
- Strong engagement with professional ethics
- Principles of human rights, equality and social justice

Joined-up consideration of which agencies have duties and powers, and how they might be applied in any given situation
Mr A: SAR Findings

Absence of proactive case coordination by commissioning CCG

Mental capacity paradox; absence of BI intervention; unlawful DoL; no CoP referral

Interface between mental capacity, mental health and physical health

Absence of safeguarding referral and action

Commissioning gap: placement shortfall

Emphasis on autonomy; attorney not involved; no OPG alert
SABs must arrange a (SAR) when:
- An adult dies as a result of abuse or neglect, or experiences serious abuse or neglect and
- There is concern about how agencies worked together to safeguard them

The purpose:
- To identify lessons to be learnt from the case and apply those lessons to future cases
- To improve how agencies work, singly and together, to safeguard adults
• Unique and complex pattern of shortcomings
  • Learning rarely confined to ‘poor practice’
  • Weaknesses in all layers of the system
  • Each alone would not determine the outcome
  • Taken together they add up to a ‘fault line’
SAR thematic findings

Learning about working together

- Lack of leadership and coordination
- Failures of communication
- Failures of escalation & challenge to poor service standards
- Failure to ‘think family’
- Absence of legal literacy
- Poor mental capacity assessment
- Collective omission of ‘the mundane and the obvious’
- Work on uncoordinated parallel lines
What makes for robust interagency working?

Shared strategic ownership and understandings

Clarity on roles and responsibilities

Turning strategy into operational reality

Interagency governance

Referral pathways

Commissioning

Forum for shared risk management

Training, supervision, support

Space for relationship-based work

Case coordination and leadership
Whole system alignment

- Legal and policy context
- Interagency governance
- Interagency features
- Organisational features
- Direct practice
- The adult
Could this happen here?

• Do you recognise any of the features of these service systems in your own work environment?
• What checks and balances are in place?
• How can you apply the learning?
• What local changes could help prevent similar outcomes?
In summary: practitioner approaches

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<th>Practice with people who self-neglect is more effective where practitioners</th>
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<tr>
<td>Build rapport and trust, showing respect, empathy, persistence, and continuity</td>
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<td>Seek to understand the meaning and significance of the self-neglect, taking account of the individual’s life experience</td>
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<td>Work patiently at the pace of the individual, but know when to make the most of moments of motivation to secure changes</td>
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<td>Keep constantly in view the question of the individual’s mental capacity to make self-care decisions</td>
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<td>Communicate about risks and options with honesty and openness, particularly where coercive action is a possibility</td>
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<tr>
<td>Ensure that options for intervention are rooted in sound understanding of legal powers and duties</td>
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<tr>
<td>Think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks</td>
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<tr>
<td>Work proactively to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals</td>
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In summary: organisational approaches

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<th>Effective practice is best supported organisationally when</th>
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<td>Strategic responsibility for self-neglect is clearly located within a shared interagency governance arrangement such as the SAB</td>
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<td>Agencies share definitions and understandings of self-neglect</td>
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<tr>
<td>Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems</td>
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<tr>
<td>Longer-term supportive, relationship-based involvement is accepted as a pattern of work</td>
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<tr>
<td>Training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in self-neglect practice</td>
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I think the only thing that will help that is concern, another human being connecting with you that’s got a little bit more strength than you, that pulls you through … that’s what keeps you alive.
Research reports


Key contacts

Please contact us if you have any queries:

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