SELF-NEGLECT: IMPLICATIONS FOR PRACTICE

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Research into:

- What is self-neglect?
- What practice dilemmas does it pose and how can we work with service users to address them?
- What causes it?
- The elements of effective practice intervention
Sources of research evidence

- Scoping the concept of self-neglect
  2011

- Addressing workforce development needs
  2013

- Exploring self-neglect practice
  2014

- Review of serious case reviews
  2015
The changing policy context for self-neglect work in England

- Replaced the No Secrets guidance
- From ‘vulnerable adults’ to ‘adults who have needs for care and support’
- SAB statutory function: to help and protect adults with care & support needs experiencing or at risk of abuse and neglect
- Self-neglect listed in Statutory Guidance to the Care Act (DH 2014) within the circumstances that constitute abuse and neglect
What is self-neglect?
No single, simple answer...

- Often treated differently in different research studies
- Different policy approaches in different countries
- Statutory Guidance to the Care Act: self-neglect “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, para. 14.7)
Self-neglect may arise from unwillingness or inability to care for oneself, or both:

- Animal collecting
- Care of daily needs (e.g., nutrition)
- ‘Diogenes syndrome’
- ‘Risky’ behaviour
- Personal hygiene
- Non-compliance with services
- Hoarding
- Living in squalor

Complexity in self-neglect?
What do we know about self-neglect? selected survey responses

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you routinely collect data about self-neglect?</td>
<td>Yes</td>
<td>9.1%</td>
</tr>
<tr>
<td>How confident are you in your answer about the volume of self-neglect cases?</td>
<td>Very confident</td>
<td>9.1%</td>
</tr>
<tr>
<td>What has been most challenging about working with self-neglect?</td>
<td>Challenges around capacity and refusal to accept help</td>
<td>76%</td>
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</table>
The well-being principle (Care Act 2014)

- Personal dignity
- Physical and mental health and emotional well-being
- Protection from abuse and neglect
- Control by the individual over day-to-day life (including over the care and support provided to the adult and the way in which it is provided)
- Participation in work, education, training or recreation
- Social and economic well-being
- Domestic, family and personal relationships
- Suitability of living accommodation
- The adult’s contribution to society
Principles of safeguarding

Empowerment
Support to make own decisions

Prevention
Taking action before harm occurs

Proportionality
Least restrictive matched to risk

Protection
From abuse and neglect

Partnership
Working together

Accountability
Clarity of role and purpose

Making safeguarding personal: it should:
- Be person-led and outcome-focused
- Engage with the person about how to safeguard them
- Find a way that enhances involvement, choice and control
- Improve quality of life, wellbeing and safety (DH, 2016, para.14.15)
The implications for practitioners

Respect for autonomy and self determination

Duty to protect from harm and promote dignity

- Practitioners may value a duty of care to protect and secure dignity, even where mental capacity is present, alongside autonomy
- Communities are also seen as having rights that counter-balance those of individuals
The key dilemma: competing imperatives

**Respect for autonomy**
- Right to make decisions others think unwise (MCA 2005)
- Limits to the power of the state (Magna Carta, the unwritten constitution)
- ECHR articles 8 and 5
- Policy context of personalisation

**Duty of care**
- The state has a duty to protect citizens from foreseeable harm
- Extreme self-neglect compromises human dignity – “surely someone could/should have done something”
- ECHR articles 2 and 3
- Others may be at risk
Practice dilemmas

• “There is a real risk around self-neglect that we drift into a place where we think we have the right to tell people what to do. And there’s a tension there, where we think we know what’s best, it’s the professional gift model...”

• “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.”

• “The combination of people who are either terrified of losing their independence or terrified of losing their relationships, 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 was just like ‘oh you’re saying it’s all fine, thank goodness, we can go away.”

• “In some cases you wouldn't intervene if they lived in the middle of a field with no-one else around them.”
Understanding why people self-neglect?

Self-neglect has been linked in the research literature to:

• **physical health issues**
  – Impaired physical functioning; pain; nutritional deficiency

• **mental health issues**
  – Depression; mental health problems; frontal lobe dysfunction; impaired cognitive functioning

• **substance misuse**
  – Alcohol; substance misuse

• **psychological and social factors**
  – Diminished social networks; limited economic resources; lack of access to social or health services; personality traits; traumatic histories and life-changing events; high perceived self-efficacy; personal values
What do people who use services have to say about their self-neglect?

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<tr>
<th>Neglect of self-care</th>
<th>Neglect of environment</th>
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<tr>
<td><strong>Demotivation</strong>: homelessness, health, loss, isolation – self-image, negative cognitions</td>
<td><strong>Influence of the past</strong>: childhood, loss, abuse, bereavement</td>
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<tr>
<td><strong>Different standards</strong>: being indifferent to social appearance, having other priorities</td>
<td><strong>Positive value of hoarding</strong>: emotional comfort, connection to something, “my family”, hobby, to be appreciated by others</td>
</tr>
<tr>
<td><strong>Inability to self-care</strong>: mental distress, physical ill-health, homelessness</td>
<td><strong>Beyond their control</strong>: voices, obsessions, physical ill-health, lack of space</td>
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What do people who use services have to say about the reasons for their situation?

“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.”

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

“I’ve noticed over the years that I didn’t give two monkeys.”

“My possessions are my family … I’m very fearful of throwing something away.”

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

“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.”

“I can’t physically bend down and pick things up.”

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

“I put everyone else first – and that’s how the self-neglect started.”
So how can we understand self-neglect?

• May involve a complex interplay between any or all of:
  – Underlying mental disorder, trauma response, and/or neuropsychological impairment
  – Physical and/or nutritional deterioration
  – Diminishing social networks and/or economic resources
  – Personal philosophy and identity

• No single overarching explanatory model captures this diversity

• Need for understanding of the meaning of self-neglect in the context of each individual’s life experience
But this can often be difficult...

Shifting responses

- Refusal or withdrawal of permission for access
- Avoidance or deflection of involvement
- Permission for access and discussion, but outright rejection of support
- Partial acceptance of input
- Full acceptance of input
What helps to get engagement when working with self-neglect?

- Recognising openness to involvement, even if ambiguous
- A sense of timing
- Keeping the door open
- Ensuring there is awareness and access to available help
- Honest recognition with service users of when they may have little or no choice in the matter
- Working with service users to provide the right kind of input: not intrusive, cost considerations, encouraging, hands-on, person-centred, going the extra mile, reliable, compassionate, understanding
What people who use services say ...

“Recognising self-neglect earlier I think is important. Once it’s recognised earlier then, like I say, 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.”

“Tenancy support started coming up but they weren’t helping, they were just leaving it for me to do. Whereas when x and his colleagues came, they were sort of hands on: ‘Bumph! We’ve got to do this’ and ‘Uh?! When you first came the first morning it’s like, ‘Well, shall we start cleaning up now?’”

“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.”

“… He sees the needs … goes that extra mile.”

“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.”
No ‘magic bullet’

What works?

- Early intervention to prevent entrenched patterns
- Combined approaches: MI, CBT, sorting, tasks
- Assistance with routine daily living
- Psychotropic medication in some cases
- Cleaning as a short term solution only
- Harm reduction, not symptom reduction

What works?
Integrating negotiated and imposed interventions

- Negotiated:
  1. Sensitive, wide-ranging interdisciplinary assessment
  2. Persistence and patience in seeking engagement and trust
  3. Care and support by consent: start with what can be agreed
  4. Support for life transitions

- Imposed:
  1. Action to terminate tenancy
  2. Enforced cleaning/clearing on environmental health grounds
  3. Do the risks of either of the above actions enable the individual to take action of their own volition?
  4. Intervention using MHA powers or MCA best interests

Understanding the individual meaning and experience of self-neglect
What service users value:

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<td>• Spotting motivation and being there at the right time</td>
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<tr>
<td>• Encouraging, person-centred; not intrusive, directive, pushy</td>
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<tr>
<td>• Going the extra mile, reliable, compassionate, understanding</td>
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<th>Intervention delivered through relationship:</th>
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<td>connection, emotional literacy, trust</td>
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<td>• Being with the person when clearing / cleaning / life changes are taking place, promoting choice where possible</td>
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<th>Support that is relevant to the service user’s own perception of needs</th>
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<td>• Practical input, equipment, benefits, housing, advocacy</td>
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<tr>
<td>• Access to mental health services</td>
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<td>• Links with others</td>
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... while practitioners highlight:

| Building rapport and trust |
| Exploring the meaning of the self-neglect |
| Working at the pace of the individual |
| Keep mental capacity constantly in view |
| Open and honest communication about risks and options |
| Clear understanding of legal powers and duties |
| Creative building on relationships and networks |
| Working proactively to engage and co-ordinate agencies |
Respect for autonomy may entail …

- Questioning the extent to which ‘choice’ is chosen
- Respectful challenge

Protection does not mean …

- Denial of wishes and feelings
- Removal of all risk

- This can require persistence rather than time-limited involvement that looks to achieve ‘independence’ before all else
- Respect for autonomy does not mean abandonment
A framework for self-neglect work

- Legal and policy environment
- Organisational context
- Individual approaches to practice
- The person

- Interagency strategy
- Shared definitions and understandings
- Clear communication and referral routes
- Scope for long-term relationship-based involvement
- Supervision that enables and challenges
Summary

- Considering the options available and being able to justify clearly the ones chosen
- Clear policy and practice emphasis on respect for autonomy - but alongside fulfilling duty of care
- Importance of ‘finding the person’ and understanding their circumstances and reasons: hearing what people have to say and ensuring they have the chance to say it

“I have come to believe that caring for myself is not self-indulgent. Caring for myself is an act of survival.” – Audre Lorde
Research reports


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