Working with adults who self-neglect: best practice evidence from research and reviews

Michael Preston-Shoot (researcher with Suzy Braye and David Orr)
Brent
December 2018
**What do we mean by self-neglect?**

<table>
<thead>
<tr>
<th>Neglect of self-care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal hygiene</td>
</tr>
<tr>
<td>Nutrition/hydration</td>
</tr>
<tr>
<td>Health</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Neglect of the domestic environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoarding: (“persistent difficulty discarding or parting with possessions, regardless of value” DSM V)</td>
</tr>
<tr>
<td>Squalor</td>
</tr>
<tr>
<td>Infestation</td>
</tr>
</tbody>
</table>

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 2017)
Self-neglect: the research evidence

- SAB governance
- Scoping the evidence on self-neglect
- Workforce development needs 2013
- Review of serious case reviews 2014-18
- Exploring self-neglect practice 2013-15
**Summary of research findings: practitioner approaches**

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

**Effective practice is best supported organisationally when**

<table>
<thead>
<tr>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategic responsibility for self-neglect is clearly located within a shared interagency governance arrangement such as the SAB</td>
</tr>
<tr>
<td>Agencies share definitions and understandings of self-neglect</td>
</tr>
<tr>
<td>Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems</td>
</tr>
<tr>
<td>Longer-term supportive, relationship-based involvement is accepted as a pattern of work</td>
</tr>
<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>
</tr>
</tbody>
</table>
Case reviews find shortcomings across the system

Learning about working together

- Lack of leadership and coordination
- Failures of communication and information-sharing
- Work on uncoordinated parallel lines
- Failure of escalation & challenge to poor service standards
- Legal literacy
- Failure to ‘think family’
- Assessments of mental capacity and risk
- Collective omission of ‘the mundane and the obvious’
East Sussex SAB: Mr A - a pen picture

• Died 24th July 2016, aged 64, Kent resident, no family contact
• Medical history: Korsakoff Syndrome, arteriovenous malformation, epilepsy, encephalopathy, type 2 diabetes, and bilateral leg cellulitis & ulceration
• Placed in nursing care in East Sussex Sept 2015, commissioned by West Kent CCG: no suitable local placement, placement search on-going, no suitable alternative
• Placement (and Deprivation of Liberty) in best interests as deemed to lack capacity to decide where to live
• Supported in decision-making by a former colleague with Lasting Power of Attorney
• Self-neglect: refusal of care and treatment
• Cause of death: systemic sepsis, cutaneous & soft tissue infection of legs, diabetes mellitus, idiopathic hepatic cirrhosis
Mr A: Key findings

- Mental health
- Legal literacy
- Interagency coordination
- Participation
- Resources
- Mental capacity
- Recording

Learning
Mr A: Recommendations

- Strengthen how agencies work together
  - Case coordination (6)
  - Placements (3)
  - Mental capacity & mental health (7)
  - Advocacy (1)
  - Dissemination of learning (4)

Safeguarding (2)
Example SCRs/SARs

- Gemma Hayter – Warwickshire – no agency took responsibility for young disabled adult
- WD – Waltham Forest – what is a lifestyle choice when living in squalor?
- Ellen Ash – Glasgow – a complex mother/son relationship, repeating pattern not addressed
- ZZ – Camden – changing behaviour not challenged by home care staff
- Mr C – Bristol (2016) – capacity assumed, impact of organisational capacity, inconsistent multi-agency working, interface between mental health and drug use, anti-social behaviour, legal literacy on section 117 MHA 1983, non-punitive approach and tenacious work by housing professionals
- YY – Camden – delays in raising concerns and commencing safeguarding enquiries; lack of contingency planning; no high level risk management meeting; procedures not well publicised or known
- Ms F - West Berkshire (2014) – complex family with co-dependent needs, tenacious and non-punitive approach by housing staff
- Adult D – Newcastle – son preventing agencies from addressing his father’s needs
- Adult A - North Tyneside – failure to collect repeat prescriptions for type 2 diabetes not noticed by the health centre; utility company did not raise an alert
- A1 – Birmingham – failure to liaise with psychiatrist over a capacity assessment and with Ambulance Trust over hospital admission
Example SARs

• Mr V – Isle of Wight (2015) – discharge planning should involve all agencies and carers, capacity assessments to be recorded, use expertise of specific healthcare professionals
• Mr W – Isle of Wight (2015) – importance of liaison between GPs and District Nurses, and sharing of safeguarding concerns across agencies; demanding workloads
• KH – Gloucestershire – importance of precise referrals, and of community nurses reporting concerns; demanding workloads; disguised compliance; lack of knowledge of adult safeguarding amongst housing providers
• Ted – Gloucestershire (2016) – district nursing service in “turmoil”, understaffed and being reorganised, importance of full information in hospital discharge letters, review repeat prescriptions, involve sheltered housing staff
• BB and CC – Islington – multi-agency meetings must share information, analysis and agree action plans; importance of liaison between GPs, OTs and care agency
• Importance of liaison, multi-agency meetings and information-exchange; medication reviews; training in mental capacity and mental health law, thorough risk and capacity assessments, supervision (South Tyneside, East Sussex, Surrey, Newcastle, Tower Hamlets, Kent and Medway, Slough)
Thematic analysis – the adult

- History – explore questions why; curiosity
- Person-centred approach – be proactive, address patterns
- Hard to reach – try different approaches, use advocates and concerned others, raise concerns, discuss risks, maintain contact, avoid case closure
- Mental capacity – ongoing assessment & review, guidance for staff regarding people with capacity who refuse services and are at risk
- Autonomy & life style choice an increasing focus (Adult A North Tyneside, B & C South Tyneside, Mr I West Berkshire, W Isle of Wight, and several Gloucestershire cases – OO, R, AT and KH)
- Carers – offer assessments, concerned curiosity & challenge, explore family dynamics and repeating patterns, engage neighbours and non-resident family members
Thematic analysis – team around the adult

- Recording – clarity & thoroughness of work done, agreed plans, outcomes achieved, discussions held
- Legal literacy – know and consider available law
- Safeguarding literacy – awareness of guidance & procedures, of risks and vulnerabilities, of safeguarding systems; adequate exploration of apparent choices
- Working together – silo working, threshold bouncing, inflexible agency responses, shared assessments & plans, liaison & challenge, follow-through
- Information sharing
- Advocacy – consider use with hard to engage people
- Use of procedures – DNAs, safeguarding alerts, risk assessments
- Standards of good practice – thoroughness of assessments, challenge professional optimism, lack of assertiveness & curiosity, authoritative practice
Thematic analysis – organizations around the team

• Support – cases are complex, high risk, stressful & demanding, so support systems essential; review scope and adequacy of policies

• Culture – encourage challenge & escalation of concerns; balance personalisation with duty of care; review case management approach

• Supervision & managerial oversight – senior managers should take responsibility for overseeing complex cases; effective supervision; use risk panels; audit cases

• Staffing – practitioners must have appropriate experience & resilience; review allocation of work; mindful of health & safety
Thematic analysis – SAB (APC) around the organizations

- Conducting SARs – involve family & carers, avoid delay
- Monitoring & action planning – robust action plans and audits of impact needed
- Procedures & guidance – develop protocols on risk & capacity assessments, follow up of service refusal, cases where adults have capacity but at risk of harm
- Use of SAR – across SABs (APCs), in training, with government departments, for procedural development
- Training – on mental capacity, law, procedures, case analysis, on person-centred approach & strategies to engage people; evidence outcomes
Key challenges of self-neglect: how can research and reviews help?

- Mental capacity
- Ethical/ideological dilemmas
- What’s going on?
- Workplace factors
- Legal literacy
- Interagency cooperation
What’s going on?

- No one overarching explanatory model
- Complex interplay of physical, mental, social, personal and environmental factors, and of (un)willingness and (in)ability
- Need for understanding the meaning of self-neglect in the context of each individual’s life experience
Understanding 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 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.
Mental capacity: affects perception of risk and intervention focus

- Respect autonomy
- Best interests: preventive
- ?
- Best interests: remedial

Self-care

Mental capacity

Self-neglect

Mental incapacity
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 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."

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

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

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 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.”
Challenging the dichotomy between autonomy and protection

Is it really autonomy when ...

- You don’t see how things could be different
- You don’t think you’re worth anything different
- You didn’t choose to live this way, but adapted gradually to circumstances
- Your mental ill-health makes self-motivation difficult
- You have impairment of executive brain function

Is it really protection when ...

- Imposed solutions don’t recognise the way you make sense of your behaviour
- Your ‘sense of self’ is removed along with the risks: “hoarding is my mind”
- You have no control and no ownership
- Your safety comes at the cost of making you miserable
A more nuanced approach

“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.”

Respect for autonomy may entail

- Questioning ‘lifestyle choice’
  - Respectful challenge; care-frontational questions

Protection does not mean

- Denial of wishes and feelings
- Removal of all risk

Autonomy does not mean abandonment
Protection entails proportionate risk reduction
Wandsworth – WWF (2017)

• A widow living alone with diagnosed multiple sclerosis. She holds strong views about the support she is prepared to accept but some care workers have developed very effective working relationships with her. Her deteriorating ability to mobilise and increasing difficulties with swallowing, transfers and hand movements has had a significant impact on her mood and ability to go out. It has become progressively difficult for her to smoke safely and there have been several small fires when she has dropped lighted matches or cigarettes, sustaining serious burns, aggravated by the emollient creams that are applied to treat skin problems. She refuses to stop smoking or to light cigarettes only when friends, family or care workers are present.

• Findings – willingness to commission agencies with specific expertise; multi-agency communication; challenge of balancing risk reduction approach with rights of adults with capacity to make choices; fire risk not part of risk assessment and management.
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? The processing information test or the impairment test?
- Impairment of executive brain function?
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

Decision-making difficulties may be masked by

- Articulate use of language; verbal reasoning skills; high perceived self-efficacy
- Decision-making “good in theory, poor in practice”

Capacity assessment to take account of

- Articulate and demonstrate models; the person in context; real world behaviour
- GW v A Local Authority [2014] EWCOP20
Effective self-neglect work: interlocking literacies

What works?
Research findings

What must and may we do?
Legal rules

Why?
Human development/mental health

How?
Relationship literacy

Organisational systems literacy
Kent & Medway – Beryl Simpson (2018)

• An older woman living with an adult daughter.
• Concerns from neighbours, family members and agencies about levels of hoarding and squalor.
• Daughter always seen. Beryl only seen once, early on, and then becomes invisible.
• Under what circumstances and using what powers can access be gained?
• Police eventually force entry; Beryl is found emaciated and seriously ill.
• Adult safeguarding power of entry available in Wales and Scotland but not in England.
The organizational 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

Reluctance to engage

Organizational pressures

“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’.”
Creating a supportive organizational environment

Supervision and support
- Recognition of the personal impact
- Support and challenge

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
A relational approach: ethical action situated within relationship

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

“Whereas when x came, they were sort of hands on: ‘Bumph! … shall we start cleaning up now?’

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.

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’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.
What makes for robust interagency working?

**Shared strategic ownership and understandings**

- Interagency governance

**Clarity on roles and responsibilities**

- Referral pathways
- Commissioning
- Forum for shared risk management

**Turning strategy into operational reality**

- Training, supervision, support
- Space for relationship-based work
- Case coordination and leadership
I think the only thing that will help ... is concern, another human being connecting with you that’s got a little bit more strength than you, that pulls you through those forms of depression, that’s what keeps you alive.
Integrating negotiated and imposed interventions
Effective practice requires whole system alignment.

- Multi-agency governance
- Organizational infrastructure
- Legal and ethical literacy
- Relationship
- The person
Research reports

Journal articles

Additional resources

**Self neglect**

**Legal literacy**

**Executive capacity**
Key contacts

Please contact us if you have any queries:

Professor Suzy Braye, s.braye@sussex.ac.uk
David Orr, d.orr@sussex.ac.uk
Professor Michael Preston-Shoot, michael.preston-shoot@beds.ac.uk