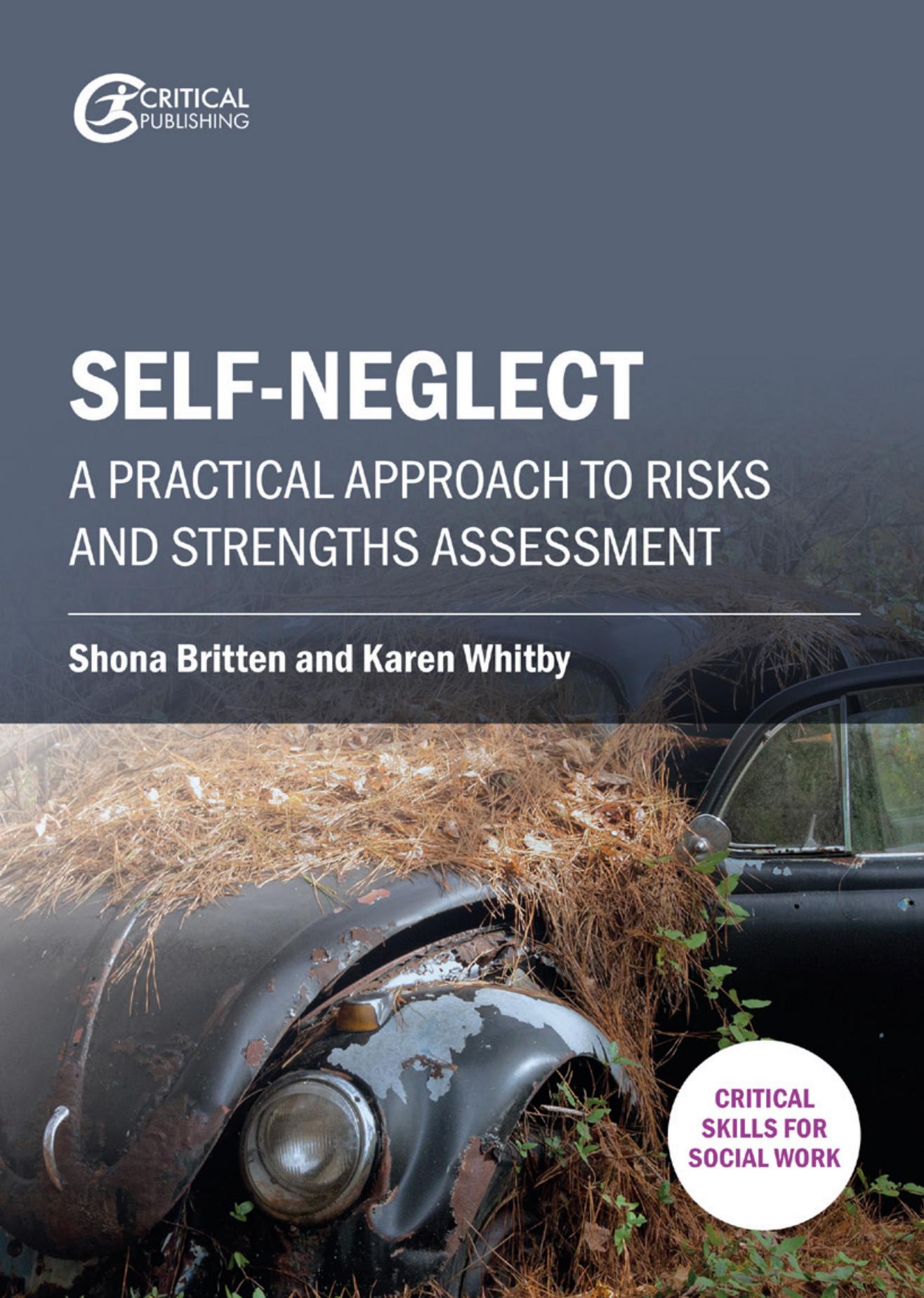


# SELF-NEGLECT

A PRACTICAL APPROACH TO RISKS  
AND STRENGTHS ASSESSMENT

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**Shona Britten and Karen Whitby**



**CRITICAL  
SKILLS FOR  
SOCIAL WORK**



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## Introduction

# Person-centred care with people who self-neglect: from principles to practice

Over recent years the world of social care, particularly in relation to work with adults, has changed dramatically. These changes have seen a shift from a focus upon social workers as the commissioners of packages of care, to more full re-engagement with the professional values of empowerment, autonomy, and person-centred control. Social workers are viewed as enabling and supportive agents of change, with interventions centred upon the achievement of the priorities and outcomes that people themselves identify and want to achieve.

The Care Act (2014) has embedded 'person-centred' practice in primary legislation, supported by guidance which has statutory status. This climate of change has posed many challenges for all involved in the world of Adult Services to enable the translation of principles into effective operational practice. Not least is the understanding of neglect and self-neglect in terms of adult social care interventions, including safeguarding. The initial moves encapsulated within the Making Safeguarding Personal (MSP) agenda placed the need to embed person-centred practice at the forefront of all interventions in order to achieve positive and inclusive Safeguarding Adults work. This focus has also raised complex questions surrounding the interfaces and interrelationships of a person-centred practice approach with people who self-neglect and the Mental Capacity Act (2005) and Human Rights Act (1998).

## Why we have written this book

This significant agenda for change prompted us, as practitioners, to look for some straightforward solutions to common-practice questions surrounding the need to respond appropriately to the increasing numbers of adults who self-neglect, or are at risk of self-neglecting, who come to the attention of Adult Services and partner agencies, commonly from concerns raised via Safeguarding Adults. This debate and search for solutions resulted in the development, for us, of a shared belief that practice-focused guidance was needed. Our thoughts have become this text, which is absolutely designed to be both meaningful and useful to practitioners

We have primarily aimed to describe a practical intervention framework and guide for a risks and strengths assessment approach in self-neglect, which supports staff who are

working with adults who self-neglect, or may be at risk of self-neglecting in the future. This framework aims to offer:

- » a multi-agency resource in relation to self-neglect as a spectrum of factors or constellation of themes and complexity;
- » practice supports for preventive, early intervention and complex case work;
- » illustrative scenario examples which inform and support practitioners;
- » a risks and strengths assessment model supported by concise practice guidance *SnapShots* which contextualise factors in self-neglect and support structured interventions.

As experienced social-work practitioners, we have designed concise practical guides to key issues and concepts in self-neglect. These we have called *SnapShots*, and have found them to be of assistance to ourselves and colleagues. The *SnapShot* format is incorporated within the text in order to prompt and focus professional discussion, ongoing development and potentially initiate further research in this multi-faceted and growing area of work which is of concern both nationally and internationally. Each chapter concludes with *Taking it Further*; this element includes references and information resources which the reader may wish to explore in order to expand their knowledge and understanding of self-neglect.

## How this book is structured

The style of this text is very much based upon meeting the practical day-to-day needs of professionals working with people who self-neglect, or are at risk of self-neglect. It can be used as an accessible resource to 'dip into' rather than as a piece of writing to be read from beginning to end. Each of the chapters, *SnapShots* and appendices can be used as standalone resources, as well as components of the comprehensive intervention framework and risks and strengths assessment model.

A brief overview of the content of each Chapter is given below in order to ease the reader's navigation of the text:

**Chapter One** discusses the concept and contextual issues associated with self-neglect and factors for multi-agency consideration. *SnapShots* included are:

- » clutter and extreme hoarding
- » Diogenes and Noah Syndromes

**Chapter Two** details a practical model intervention framework for use in self-neglect cases, with illustrative examples and sample document formats. This suggested model is supported by full guidance notes and a set of *SnapShots*; these are:

- » decision-making and disengagement

- » information-sharing
- » equality and diversity
- » fluctuating capacity
- » Lasting Power of Attorney (LPA)
- » independent advocacy
- » co-production
- » advance support planning

**Chapter Three** contains a risks and strengths assessment model, supported by full guidance notes, illustrative examples and sample document formats, including *SnapShots* which summarise:

- » driving and restraining forces to consider when utilising a conceptual risk assessment model – a human perspective
- » criminal offences and safeguarding adults
- » domestic abuse
- » The Modern Slavery Act (2015)
- » exploitation and illegal drug use
- » grooming
- » mate crime

**Chapter Four** looks at illustrative case scenarios using the risks and strengths assessment model framework and associated example documentation. A descriptive ‘volcano effect’ graphic is included as a visual learning tool.

**Chapter Five** considers the Care Act (2014) ‘well-being’ principle in self-neglect and Safeguarding Adults work. The *SnapShots* included in this chapter are:

- » balancing attitudes and values in person-centred safeguarding
- » The Care Act (2014) and supporting carers
- » a person in a position of trust

**Chapter Six** suggests an approach, developed by the authors, to building sustainable community strength and resilience. This model directly relates to and interfaces with the role of agencies represented on locality Safeguarding Adults Boards, in addressing self-neglect and the people who are at risk of self-neglect living in their area. The *SnapShot* in this chapter describes a suggested personalised community consolidation model of practice which places the person at the centre of all interventions from the individual through to multi-agency planning and decision-making.

The three appendices we have included with this work are:

1. A *SnapShot* Guide to the Mental Capacity Act (2005)
2. A *SnapShot* Guide to the Mental Health Act (1983) – rights, powers and protection
3. A *SnapShot* Guide to terminology in Safeguarding Adults

Our aim will have been met if practitioners find the content and format of our work informative and most importantly useful, as well as if it supports multi-agency planning and practice to converge in consistently achieving positive outcomes with adults at risk.

### Introduction

This chapter discusses the concept and context of issues associated with people who self-neglect. It includes:

- » examples of behaviours we have identified through our work with adults of all ages who self-neglect and are those which practitioners may come across in their work;
- » what the *Care and Support Statutory Guidance* says about responses to self-neglect;
- » multi-agency considerations in this complex area of work;
- » a table outlining five Safeguarding Adults Reviews where self-neglecting behaviours were a factor;
- » *SnapShots* on:
  - » clutter and extreme hoarding;
  - » Diogenes and Noah Syndromes.

### What the the Care Act (2014) says about self-neglect

There are many varying complexities associated with the concept of 'self-neglect'; these have been recognised in both national and international research on the subject and are defined as priorities for action within the Care Act (2014); paragraph 14.17 of the Statutory Guidance states:

*Self-neglect may not prompt a section 42 enquiry. An assessment should be made on a case by case basis. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support.*

## Factors associated with self-neglect in adults from practice

There are many presenting factors and behaviours which may, in varying combination, be indicative of self-neglect in adults. This wide range of factors can include, but are not limited to, the following examples:

- » The failure of an individual to manage their physical and/or mental health, eg not taking medicines as prescribed; not seeking medical assistance and/or examination when needed; inadequate food, water and/or clothing; inadequate personal safety.
- » Their involvement with individuals or groups which cause them harm, from which the individual is unable to withdraw, eg financial exploitation, physical assault.
- » Unstable and inadequate housing, eg 'sofa-surfing', the threat of eviction from a rented property, living in a privately owned property which is unsafe.
- » Environmental hazards within their home environment, eg problematic hoarding of objects and/or animals, lack of basic utilities, squalor.
- » Social isolation and exclusion.
- » Impaired cognition and/or physical disabilities, eg learning difficulties, mental health condition (including dementia-type conditions).
- » Lack of insight or will to undertake essential daily hygiene/care tasks; the individual *may or may not* have mental capacity as defined within the requirements of the Mental Capacity Act (2005) Chapter Two, or they may experience fluctuations in their capacity to make a specific decision at the time the decision needs to be made. Fluctuations in mental capacity may be severely influenced by the abuse of alcohol or drugs, or prescribed medicines.

NB: This is not an exhaustive list.

## Multi-agency considerations

Despite the acceptance of self-neglect as a matter of concern for the individuals themselves, agencies and the wider public, difficulties in achieving positive outcomes for the person concerned remain; this can be due in part to some of the points identified below:

- » Those supporting the person who is self-neglecting are often unaware of which other agencies can offer input, support and advice.
- » Some organisations and agencies have not prioritised or given consideration to the long-term issues of self-neglect and historically have not engaged fully with multi-agency responses.

- » People can 'fall through the gap' of services, and their situations can deteriorate to a catastrophic level without input.
- » The allocation of resources between organisations and agencies may often not be effectively coordinated.

Self-neglect is complex and multi-faceted; it can cover areas of responsibility held by all local statutory agencies including the Police Authority; Fire and Rescue Services; Environmental Health Departments; NHS Trusts; Clinical Commissioning Groups; Adult Social Care; Housing Departments; Probation Services; Multi-agency Public Protection Arrangements (MAPPA); Multi-agency Risk Assessment Conferences (MARAC); RSPCA; Children and Families Social Care; as well as Safeguarding Adults Boards and Safeguarding Children Boards.

Due to the diversity in presentation of self-neglect this can lead to devastating and catastrophic outcomes for the individual, when not recognised and addressed by the organisations and agencies involved. In these cases the organisations and agencies can find themselves placed in vulnerable and potentially serious situations in safeguarding due to a lack of clear understanding regarding:

- » the extent to which self-neglect is prevalent in their areas of responsibility;
- » the nature of self-neglecting behaviours and their impact upon the health, well-being and safety of the individual themselves and others, both current and in the future;
- » priorities for service developments and commissioning to meet the future need.

## Safeguarding Adults Reviews (SARs)

Safeguarding Adults Boards (SABs) have a statutory duty under the Care Act (2014) Section 44 to arrange for a Safeguarding Adults Review (SAR) to be undertaken in particular circumstances. The *Care and Support Statutory Guidance* (paragraphs 14.162–63) confirms the circumstances in which a SAR should be undertaken:

- » *SABs must arrange a SAR when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult;*
- » *SABs must also arrange a SAR if an adult in its area has not died, but the SAB knows or suspects that the adult has experienced serious abuse or neglect. In the context of SARs, something can be considered serious abuse or neglect where, for example the individual would have been likely to have died but for an intervention, or has suffered permanent harm or has reduced capacity or quality of life (whether because of physical or psychological effects) as a result of the abuse or neglect. SABs are free to arrange for a SAR in any other situations involving an adult in its area with needs for care and support.*

The records of cases which have sadly led to the death of an adult, for whom self-neglect was a factor in their life, included within published SARs and those reports previously known as Serious Case Reviews (SCRs), can provide vital resources of ‘lessons learned’ and action plans implemented; examples are contained below in [Table 1.1](#). The translation of ‘lessons learned’ into core operational procedure remains an area for ongoing development, which requires the membership of SABs to achieve clarity regarding the prevalence rates in their own area in order to support local and national service design and commissioning priorities; this relationship is described by the authors as Personalised Community Consolidation and is discussed in [Chapter 6](#).

**Table 1.1** Safeguarding Adult Review examples

Case	Overview Context	Reference
<p>Deceased female adult (43 years of age). Cause of death: liver failure; alcohol cirrhosis; renal failure; septicaemia; infected fracture.</p> <p>Author’s note: Potential for fluctuations in mental capacity while under the influence of alcohol (not documented within available report).</p>	<p>History of alcohol abuse. Insanitary living conditions: ‘Police found the house to be in a very poor state with faeces and urine on the floor.’ Reluctance to accept support. History of domestic violence. Mental health assessment concluded no severe or enduring mental illness.</p> <p>Previous CVA – aged 39 years (approx.), resulted in speech difficulties.</p>	<p>Serious Case Review regarding X. Cornwall Safeguarding Adults Board 2008</p>
<p>Deceased male adult. Cause of death: pneumonia; paranoid schizophrenia; inanition (starvation). Date of death: not known; pronounced dead: 25/03/2009 (found in his home). Mental capacity was assumed.</p>	<p>Misuse of prescribed and ‘over-the-counter’ medicines. Poor physical health; ‘pressure sores’; concerns regarding the home environment – signs of self-neglecting behaviours.</p> <p>Depression; anxiety; behavioural problems; paranoid schizophrenia (partial lobotomy surgery); gastric problems.</p>	<p>Serious Case Review relating to A1. Worcestershire Safeguarding Adults Board April 2010</p>

Case	Overview Context	Reference
Deceased male adult (42 years of age). In line with Mental Capacity Act (2005) principles Mr AA was presumed to hold mental capacity.	Self-neglect of personal hygiene, diet and home environment. Lack of availability of prescribed medicine.  Schizophrenia.	Safeguarding Adults Review Mr AA. Norfolk Safeguarding Adults Board June 2015
Deceased male adult (under 65 years of age). Cause of death: 'sudden unexpected death in alcohol and peripheral vascular disease'. The Coroner confirmed 'that Mr I had been dead for some days.' Assessed to hold mental capacity to decide where and how he lived his life.  Author's note: Potential for fluctuations in mental capacity while under the influence of alcohol.	Refusal to accept commissioned care and support services to meet essential personal health and social care needs. Ongoing involvement from local health and social care professionals. Self-neglect of personal health, prescribed medicines, diet and home environment to insanitary levels.  Brain injury; lower leg amputation. History of depression. Severe dependence on alcohol.	Safeguarding Adults Review Mr I. West Berkshire Safeguarding Adults Board July 2016

It is vital to identify the nature of self-neglect, as well as the extent and impact of it on a case-by-case basis, as the support and/or intervention which may be required is unique to the person at the centre of the situation. It is recognised that there are people who present self-neglecting behaviours who, even with ongoing involvement and intervention, will not cooperate and engage with support planning. In these circumstances it is for the Lead Agency involved to consider statutory duties and responsibilities in line with current legislation; a brief overview of applicable legislation at the time of writing is given below in the *SnapShot on ... clutter and extreme hoarding* (this is not exhaustive, and is not designed to provide any form of legal guidance).

Practice experience has, with retrospective review, supported the authors to promote the use of a clear and concise risks and strengths model of assessment by practitioners across all applicable agencies. This model of intervention addresses the serious concerns of self-neglect from a person-centered perspective and is described in detail in [Chapters 2 and 3](#).

## Practice matters ...



### Snapshot on ... Self-neglect

Key issues to consider with adults of all ages who self-neglect are:

- » Abuse, exploitation and criminal activity, which may also involve and/or impact upon children or other adults at risk who also reside within the property.
- » Historical information in relation to childhood neglect and disordered attachment.
- » Robust and consistent Risk Assessment, which identifies *hazards*, balanced with *strengths*, required/agreed *actions* focused upon the individual's views of their needs, and their ability to undertake and complete identified tasks.
- » The need for Advocacy.
- » Other agencies which can offer input, support and advice.
- » The longer-term issues of self-neglect and multi-agency involvement.
- » People who have or are at risk of 'falling through the gap' of services; it is known that these types of situation can deteriorate to a catastrophic level without input.
- » The effective coordination and allocation of resources between organisations and agencies.



### Snapshot on ... Clutter and extreme hoarding



Clutter and extreme hoarding are facets of the broader issue of self-neglect. A simple definition of this is one of the refusal or impotence of an individual to safely manage

and maintain their personal health, safety and well-being; this may be characterised in many ways including the maintenance of a safe living environment.

The classic presentation of clutter and extreme hoarding includes the hazardous accumulation of items which have no continuing use, and are NOT part of an ongoing or previous interest; such items can include old foodstuffs, packaging, newspapers, magazines and circulars as well as excrement. These behaviours can include the hoarding of animals in an unmanaged and chaotic manner; this is further discussed within the *SnapShot on ... Diogenes and Noah syndromes* below.

This type of self-neglecting behaviour and presentation can and does pose challenges for those involved with a person living in these circumstances as they may either refuse or be impotent to address the safety issues raised. People who hoard may have an acute association with their possessions, and refuse to regard them as hazardous and problematic to themselves and/or others. This pattern of extreme behaviour can be of significant detriment to the health and well-being of the occupant(s) of the property and potentially their neighbours. These risks can include infestation by rodents and insects, as well as fire risk and animal safety.

This situation requires a steady, dedicated and coordinated multi-agency approach with the involvement of potentially a range of statutory agencies in order to achieve safe and sustainable solutions. The accurate assessment of the individual's mental capacity is critical in these circumstances. In relation to the hoarding of animals, applicable animal safety agencies should be contacted immediately.

The completion of consistent and person-centred risk assessment, with the individual concerned, should recognise their strengths and personal solutions to the situation alongside legal responsibilities, which in England and Wales currently includes (in brief):

- » The Care Act (2014)
- » Mental Capacity Act (2005)
- » Mental Health Act (1983)
- » Human Rights Act (1989)
- » Animal Welfare Act (2006)
- » Environmental Protection Act (1990)
- » Public Health Act (1936)
- » Police and Criminal Evidence Act (1984)
- » Gas Act (1986) and Electricity Act (1989)
- » Housing Act (2004)



## SnapShot on ... Diogenes and Noah syndromes

Rejection  
 Contamination  
 Isolation  
 Animals  
 Infestation  
 Extreme Hoarding  
 Infirmity  
 Self-Neglect  
 Unhealthiness  
 Squalor

Diogenes syndrome was included within the 'Diagnostic and Statistical Manual of Mental Disorders', 5th Edition (DSM-5; *American Psychiatric Association*, 2013) as a behavioural condition which is typified by self-neglect, extreme hoarding, and environmental squalor; it is commonly associated and prevalent within the older adult population who reject available support and appear to lack insight into the risks and hazards.

Diogenes syndrome is named after the ancient Greek philosopher Diogenes of Sinope, who lived circa 412–323 BC. Diogenes was a contemporary of Plato, and is reported to have frequently challenged Plato's philosophical thinking and teachings. Contrary to the factors which are used to identify or diagnose Diogenes syndrome, it is reported that the man himself rejected all material possessions and lived, at times, in a large barrel.

Noah syndrome is described as a form of Diogenes syndrome in an article by Alejandra Saldarriaga-Cantillo MD and Juan Carlos Rivas MD. This research paper notes that in addition to the characteristics recognised as features in Diogenes syndrome the person affected will also hoard a '*large number of animals, neglecting their basic care and showing an inability to recognize the consequences this may have for the health and well-being of both the animals and the patient themselves.*' (Saldarriaga-Cantillo and Rivas, 2015, pp 1–2).

The acquisition of animals may occur passively, in that the person may have them given to them to be cared for or alternatively they may actively seek them out; in both cases the risk of uncontrolled reproduction is a key factor.

This syndrome may in part be so called in reference to Genesis Chapter 6: 19/20, where the instructions given to Noah included:

*You are to bring into the ark two of all living creatures, male and female, to keep them alive with you.*

*Two of every kind of bird, of every kind of animal and of every kind of creature that moves along the ground will come to you to be kept alive.*

and Genesis Chapter 7: 2/3:

*Take with you seven pairs of every kind of clean animal, a male and its mate, and one pair of every kind of unclean animal, a male and its mate, and also seven pairs of every kind of bird, male and female, to keep their various kinds alive throughout the earth.*

In summary, this chapter has aimed to describe the multi-faceted nature of self-neglect and the need for a case by case approach to be taken by practitioners in the evaluation and planning of practice interventions with the person at the centre of all activities. Its purpose has also been to inform, prompt and focus further ongoing work for SABs and their partner agencies to engage fully with understanding the risks associated with self-neglect to ensure that service design and commissioning meets their community's priorities.

## Taking it Further

### Publications

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