The conundrum of self-neglect

FACTORS DRIVING SELF-NEGLECT

Most clinicians will encounter cases of self-neglect during their career, which will vary from mild presentations to really disturbing cases where the self-neglect becomes extreme. Often it is difficult to comprehend how people would choose to live in such dreadful circumstances, but trying to resolve this feels like a series of insurmountable obstacles. What drives such behaviour and how do we manage it?

Literature and history contain many references to behaviours that appear to be self-neglect and give us an insight into possible underlying motivations. For centuries, self-purification through neglect has been a recognised pathway for those striving to be nearer to the divine, and can be seen in the life histories of many sanctified individuals in key world religions. With hindsight, histories such as that of St. Simeon Stylites, who took refuge upon a pillar and stood there for as long as his legs would sustain him (37 years on a small platform on top of a pillar near Aleppo),¹ despite the effects this had on his physical integrity, appear to possibly fall into this category.

Others become reclusive and neglectful in response to emotional hurt, perhaps most vividly in Dickens' novel of 1860, *Great Expectations*, with Miss Havisham sitting at her spider-infested wedding table surrounded by rotting food.² We also know that those who have suffered extreme persecution, trauma, and hardship may develop hoarding behaviours, which become neglectful when the hoarding becomes extreme and the collections start to include refuse and decay.³ Solidarity of suffering also drives others in self-neglectful behaviours, such as the philosopher Simone Weil, who refused to eat in support of her resistance comrades in occupied France.⁴

Many GPs will have visited these households. Some are difficult to forget: the

house call undertaken where the district nurse who got there first is vomiting in the garden when you arrive; the elderly lady who has literally not moved from her armchair for over a week; and the room half filled with a floor-to-ceiling mountain of newsprint, which you watch warily from the corner of your eye in case something suddenly erupts out of it. Coping with the environment and not showing any facial reaction tends to take every ounce of energy. It is not unusual to find that carers have recorded a gradual disintegration over many months, but have not alerted anyone to the circumstances. Trying to improve the lot of these patients may appear impossible and can be frustrating. In many cases the situation continues until a major crisis occurs.

DOES THE INDIVIDUAL HAVE CAPACITY?

The question of capacity and choice is key, and in many areas the first question asked is does this individual have capacity? If the answer to this is in the affirmative, it may be difficult to obtain a visit from a social worker or a mental health team. Once self-neglect is extreme, however, it is often difficult to see how it is possible to define that individual as making capacitous decisions.

There is a difference between having the capacity to make decisions and having the capacity to identify and extract oneself from harmful circumstances.

Naik *et al* propose a very clear and helpful framework for looking at these types of capacity.⁵ This involves looking at whether decision making is capacitous in the context of self-care and protection, and they provide a set of standardised questions in order to gain clear understanding of both decision making and executive capacity. They argue that capacity for self-care and protection should be seen as a gradient rather than an all or nothing phenomenon. Trying to assess patients who self-neglect requires building a long-term picture of

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what causes their behaviour to become neglectful and their previous attitudes to self-care. It is important to exclude both mental and physical illness (for example, the possibility of hypercalcaemia or a brain tumour) underlying their behaviours, and understand any previous life events that may explain their current situation. It is made very clear by the Social Care Institute for Excellence that 'the presence of mental capacity is not used as a justification for inaction'.⁶

A simple question 'Do they have capacity?' is not enough.

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