## How to: assess mental capacity in cases of self-neglect and refusal of services

Self-neglect covers a range of behaviours that manifest as an unwillingness or inability to care for oneself and/or one's environment, including:

- Lack of self-care e.g. neglect of personal hygiene, nutrition, hydration and/or physical health, thereby endangering safety and well-being and/or
- Lack of care of one's environment e.g. squalor and hoarding and/or
- Refusal of services that would mitigate risk of harm.<sup>1</sup>

This broad definition is reflected in <u>Care Act 2014 statutory guidance</u>, which includes self-neglect as a category under adult safeguarding and states that 'This covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding...' <sup>2</sup>

Risk assessment is crucial to determining what interventions/actions are required in self-neglect cases. Often, the adult will refuse the proposed intervention/actions and this will often trigger an assessment of their mental capacity to make this decision. In some cases, the assessment will relate to the adults' mental capacity to consent to or refuse services aimed at making their home safe and habitable (e.g. help to discard of hoarded items, repairs, 'blitz' cleaning and fire safety checks). In other cases, the assessment will relate to the person's mental capacity to consent to or refuse services aimed at mitigating the risks posed by neglect of self-care (e.g. provision of care and support to provide assistance with personal care, meals on wheels, laundry and support with physical health needs). In extreme cases, when the person's self-neglect has reached the point where it is no longer safe for them to remain at home, the decision will centre on admission to residential care or supported living.

## The presumption of mental capacity and practicable steps

As per the first principle of the MCA, a person must be presumed to have mental capacity to make their own decisions. However, this principle should never be used to justify non-intervention. A judge recently pointed out 'When there is good reason for cause for concern...the presumption cannot be used to avoid taking responsibility for assessing and determining capacity.' <sup>3</sup> Furthermore, the MCA Code of Practice states that mental capacity should be assessed when '...the person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision.' <sup>4</sup>

Before concluding that a person lacks mental capacity to make a decision, it is important to take all practical and appropriate steps to enable the person to make the decision themselves (2<sup>nd</sup> principle of the MCA). Chapter 3 of the MCA Code of Practice gives detailed guidance on the steps that could be taken to support a person to make a decision for themselves including: providing relevant information, communicating in an appropriate way, making the person feel at ease and supporting the person. In relation to self-neglect, this is likely to include:

- Helping the adult to understand the consequences and risks of their behaviour.
- Considering whether there is anyone who can help you to engage with the adult (e.g. family, advocate, other professional).
- Avoiding the use of stigmatising language such as referring to the person as a 'hoarder' or referring to their possessions as 'rubbish'.

<sup>&</sup>lt;sup>1</sup> Braye et al 2015, Self-neglect policy and practice: research messages for practitioners. London: (SCIE)

<sup>&</sup>lt;sup>2</sup> See paragraph 14.17

<sup>&</sup>lt;sup>3</sup> See paragraph 26 of *Royal Bank of Scotland Plc v AB* [2020] UKEAT 0266 18 2702

<sup>&</sup>lt;sup>4</sup> See paragraph 4.35, p. 52

### **Relevant information**

Since self-neglect encompasses such a wide range of behaviours, the relevant information that a person needs to understand, retain and use or weigh, will vary from case to case. However, it is likely to include:

- The nature or character of their self-neglect e.g. whether it manifests as lack of self-care (neglect of personal hygiene, nutrition and hydration and/or health) and/or lack of care of one's environment (hoarding and living in squalor).
- The reasonably foreseeable consequences of their self-neglect. For neglect of environment (including hoarding) this may include:
  - The fire risk
  - The falls risk
  - Deteriorating physical health
  - The risk of enforcement action being taken (e.g. by landlord or local authority under public health legislation).
- For neglect of self-care, the risks are likely to include:
  - The risk of infection
  - The risk of pressure ulcers
  - The risk of malnutrition/dehydration
  - Deteriorating physical health and death.
- The proposed intervention/actions required to mitigate the risks of harm. This may include: provision of a package of care to support the person with personal care, nutrition and hydration and their physical health needs; support to de-clutter their environment, 'blitz' cleans and ongoing assistance with cleaning; arranging a fire safety check from Leicesterhire Fire & Rescue Service.

## Carrying out the assessment

A mental capacity assessment is a dynamic process of providing the relevant information to the person and then asking the person questions to assess their ability to understand, retain, use or weigh that information, and communicate their decision. It may be necessary to provide the relevant information more than once and in different formats. For example, if a person doesn't understand something the first time, it would be appropriate to explain it in a different way using a different method. Due to the complexity of self-neglect, the mental capacity assessment may need to be carried out over several visits.

It is fundamental to the assessment process that the adult is informed of the purpose of the assessment.<sup>5</sup> This involves explaining to the person the reasons why the assessment is being carried out and that you have a duty to ensure that they are making informed decisions about their lifestyle/refusal of services.

## **Understanding the relevant information**

The case law is clear that 'It is not necessary for a person to demonstrate a capacity to understand and weigh up every detail of the respective options, but merely the salient factors.' <sup>6</sup> Similarly, assessors '...must guard against imposing too high a test of capacity...because to do so would run the risk of discriminating against people suffering from a mental disability.' <sup>7</sup> Questions should therefore aim to elicit whether or not the adult has a basic understanding and awareness of the salient issues.

<sup>&</sup>lt;sup>5</sup> Paragraphs 47-49 of <u>LB Wandsworth v M & Ors [2017] EWHC 2435</u>

<sup>&</sup>lt;sup>6</sup> Paragraphs 22 & 69 of KK v STCC [2012] EWCOP 2136 [2012]

<sup>&</sup>lt;sup>7</sup> Paragraph 16 of <u>PH v A local authority [2011] EWCOP 1704</u>

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After giving the adult **the relevant information** (see the box on the first page), potential questions to ask to assess the person's ability to understand it could include:

## Neglect of personal hygiene e.g. not washing or changing clothing and/or unmet continence or toileting needs:

- Do you have any problems with washing/bathing/showering?
- Do you have any problems with incontinence and/or toileting?
- How do you keep yourself clean/maintain your personal hygiene?
- How often do you wash/bathe/shower?
- How often do you wash your clothes?
- How could carers help you to stay clean/maintain your personal hygiene?
- How could incontinence pads help you to stay clean/maintain your personal hygiene?
- What are the risks/consequences of poor personal hygiene?

### Neglect of nutrition/hydration e.g. not eating or drinking enough to maintain physical health:

- Do you have any problems with shopping or meal preparation?
- Why is it important to eat regular meals and drink enough?
- What would happen to you if you didn't drink enough fluids?
- What would happen to you if you didn't eat enough food?
- Can you stay healthy if you just drink alcohol?
- How could carers help you with shopping and meal preparation?
- How could meals-on-wheels help you?

### Neglect of physical health e.g. wound care and/or poorly managed chronic health conditions:

- Do you have any pressure ulcer(s)/open wound(s)? If so, where are they?
- What do you need to do to care for your ulcer(s)/wound(s)?
- How could a district nurse/practice nurse/carers help you care for your ulcer(s)/wound(s)?
- What could happen if your pressure ulcer(s)/wound(s) become infected?
- What can you do to prevent your ulcers/wounds from becoming infected?

### Neglect of environment e.g. hoarding, living in squalor and associated risks:

- Do you have any problems moving around your home and using all the rooms?
- Does your home pose any risks to your health and wellbeing?
- Your possessions are piled up around your home. What risks does this pose (e.g. falls risk, fire risk)?
- Your house is filled with potentially flammable possessions (e.g. newspapers). What might happen if there was a fire?
- What are the risks of using a bar/gas heater (e.g. fire risk, risk of asphyxiation)?
- What are the risks of using a BBQ/camping stove in an enclosed space (e.g. fire risk, risk of carbon monoxide poisoning)?
- How would you get out of your property if there was a fire (if exits are blocked by hoarded possessions)?
- How could a fire-safety check improve your safety?
- If you don't reduce the amount of your possessions, what action might your landlord take?
- Do you have any problems keeping your home clean?

<sup>8</sup> For an example, see the case of <u>Robert Crane</u>
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- What are the risks of urinating and opening your bowels in a toilet that doesn't work/toileting on the floor/toileting in the garden or street/storing faeces and urine?
- How could a blitz clean and/or carers help you keep your home clean?
- If you don't keep your home clean, what action might your landlord take? What action might the council take?
- Your windows are broken. What problems might this cause you (e.g. hypothermia and lack of security)?
- Why do you need heating? What are the risks/consequences of living in a cold home?

## Retaining the relevant information

Section 3(3) of the Mental Capacity Act 2005 states that 'The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.' Therefore, if information can be retained long enough for the adult to make the decision, that is sufficient, even if they cannot then retain that information for a longer period.

To assess the adult's ability to retain information, it is likely that the same methods and tools used to provide the relevant information and assess understanding will need to be used again. For adults who have good verbal communication, it would be appropriate to ask them to recite the key points of the relevant information. For adults with communication difficulties, it may be appropriate to use written words or visual aids to establish whether the adult recalls the key information a short while after it has been provided.

## Use or weigh the relevant information

This part of the assessment will build upon questions asked to assess the adult's understanding of the relevant information. The aim is to determine whether the adult is '...able to employ the relevant information in the decision-making process and determine what weight to give it relative to other information required to make the decision.' <sup>9</sup> It is therefore necessary for the adult at risk to be able to apply the relevant information to themselves and balance the benefits and harms of the choices they are making. Another way of putting it is, can the person having understood the information, take account of it?

To assess the adult's ability to use or weigh information, questions should aim to find out how they make decisions about their lifestyle and/or refusal of services and what factors they have taken into account. Equally important are the values that influence how they weigh up information. Potential questions to ask include:

### Neglect of personal hygiene e.g. not washing or changing clothing and/or unmet continence or toileting needs:

- Is it important to you to maintain a good standard of personal hygiene? Why?
- Do you consider yourself to have a good standard of personal hygiene? Why?
- Why do you think others are concerned about your personal hygiene?
- How would you feel/what are your views about having support from carers with personal care and/or laundry? What are the risks of refusing this support?
- How would you feel about a referral to District Nurses for a continence assessment? What are the risks of refusing this support?
- If the bathroom/toilet is not functional, point this out to the person and ask: What needs to be done to fix your bathroom/toilet? Do you need any support with this? If not, why?

## Neglect of nutrition/hydration e.g. not eating or drinking enough to maintain physical health:

- Do you think you are eating and drinking enough to stay healthy?
- Why do you think others are concerned about the amount you are eating/drinking?

 <sup>&</sup>lt;sup>9</sup> See paragraph 38 of Kings College Hospital NHS Trust v C and V [2015] EWCOP 80
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- How would you feel/what are your views about having support from carers with shopping and/or meal preparation? What are the risks of refusing this support?
- How would you feel/what are your views about having meals on wheels? What are the risks of refusing this support?
- If kitchen facilities are not working or unusable, point this out and ask: What needs to be done to fix your kitchen? Do you need any support with this? If not, why?

## Neglect of physical health e.g. wound care and/or poorly managed chronic health conditions:

- Why do you think others are concerned about the way you manage your ulcer(s)/wound(s)?
- How would you feel/what are your views about having support from district nurse/practice nurse/ carers with your ulcer(s)/wound(s)? What are the risks of refusing this support?
- If the adult's ulcer(s)/wound(s) are malodourous and in extremis infested with maggots, <sup>10</sup> point out that they need urgent medical attention and subsequently ask: What are the consequences if you don't get urgent medical help?

#### Neglect of environment e.g. hoarding, living in squalor and associated risks:

- Why do you think others are concerned about the amount of your possessions/the cleanliness of your home/the fact that you have no heating etc?
- Do you think you might have a problem getting rid of possessions you no longer need?
- How do you feel about the amount of possessions in your home and/or condition of your home? Is there anything you would like to change?
- How would you feel/what are your views about a person you trust helping you to reduce the amount of your possessions? What are the risks of continuing as you are?
- How would you feel/what are your views about having a blitz clean/ongoing support with cleaning? What are the risks of refusing this support?
- How would you feel/what are your views about having a fire safety check? What are the risks of refusing this support?
- If there is no heating/the property is in a state of disrepair (e.g. broken windows, leaking roof, toilet not functional etc) point this out and ask: What needs to be done to make your home warmer/improve the safety and/or security of your property? Do you need any support with this? If not, why?

There are two common areas of difficulty in assessing whether a person can use or weigh information. The first is where a adult denies factual information about a situation. For example, a adult denying or refusing to accept that their self-neglect poses any risks to their safety and wellbeing. Here it is important to ensure that the evidence of harm is presented objectively, to support the person's acceptance of it. Where appropriate, this could include providing documentary evidence, such as risk assessments, incident reports, medical reports, ambulance service alerts. If hoarding is an issue, it would be appropriate to provide information about the fire risk. If denial persists, it may be necessary to then respectfully question or challenge false beliefs or assumptions. If the person continually refutes the evidence, then this would indicate an inability to use or weigh relevant information. Conversely, if the adult at risk accepts the relevant information, the weight they attach to that information is a matter for them and will depend on their own values or outlook. This may result in the adult at risk making an unwise but capacitated decision.

<sup>&</sup>lt;sup>10</sup> For an example, see the case of Adult A

<sup>&</sup>lt;sup>11</sup> See <u>London Fire Brigade's Hoarding Disorder video</u>

<sup>&</sup>lt;sup>12</sup> See paragraph 38 of <u>Kings College Hospital NHS Trust v C and V [2015] EWCOP 80</u>

<sup>2020</sup> Guidance designed by Leicestershire County Council and edited by Edge Consultation to support Training

The second area of difficulty is where the adult gives coherent answers to questions but is then unable to translate their intentions into actions due to executive dysfunction. The adult says one thing but then does something else in practice. Executive functioning has been described as, '...the ability to think, act, and solve problems, including the functions of the brain which help us learn new information, remember and retrieve the information we've learned in the past, and use this information to solve problems of everyday life.'<sup>13</sup>

It may be necessary to gather further collateral information and ask further probing questions if there appears to be a mismatch between the adult's words and their actions. It would be legitimate to conclude that the adult lacks mental capacity to make a decision if they are unaware of or deny the fact that they cannot implement their stated intentions, or deny that when needed they are unable to bring to mind the information required to implement a decision. However, it would only be legitimate to reach such a conclusion where there is clearly documented evidence of repeated mismatch. For example, if during the assessment, the adult understands the relevant information and is able to use or weigh it and agrees to support services but then subsequently fails to engage, it would be appropriate to ask the person the reasons why and explore the mismatch between their words and actions. If they are aware of and accept their difficulties and the associated risks, but choose to continue to refuse interventions to mitigate risks, then this would be deemed an unwise decision rather than a lack of mental capacity.

#### Communicate the decision

To have mental capacity to consent to or refuse the proposed intervention/actions, the adults needs to have a method of communication that is consistent and reliable enough to respond to questions and eliminate any ambiguity. This is an area where it is particularly important to show that you have taken practicable steps to facilitate communication. For example, reproducing as best as possible the manner by which they usually communicate, providing all necessary tools and aids, and enlisting the support of carers, friends or professionals who may be able to facilitate communication.

#### After the assessment

Reflect upon the following points:

- Do you have enough information to displace the presumption of mental capacity?
- Do you need to carry out further visits to make a judgment?
- Remember the assessment of mental capacity is made on the balance of probabilities.
- Have you established the causative nexus (e.g. the causal link between inability to decide and the
  identified impairment of or disturbance in functioning of the mind or brain)? A formal diagnosis is not
  required.

#### **Outcomes**

### 1. The adult has mental capacity to make decisions about their self-neglect/refusal of services

At this point the Mental Capacity Act no longer applies. However, in high risk cases, consideration should be given to whether the adult meets the criteria for detention under s.2 of the Mental Health Act 1983 (MHA). As a last resort, the local authority should consider bringing proceedings under the Inherent Jurisdiction of the High Court.

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<sup>&</sup>lt;sup>13</sup> See paragraph 39 of A Local Authority v AW [2020] EWCOP 24 (20 May 2020)

<sup>&</sup>lt;sup>14</sup> 39 Essex Street - <u>Carrying out and recording capacity assessments (June 2020)</u>

<sup>&</sup>lt;sup>15</sup> S.2 of the MHA 1983: 'An application for admission for assessment may be made in respect of a patient on the grounds that—(a) he is suffering from mental disorder of a nature or degree which warrants the detention of the patient in a hospital for assessment (or for assessment followed by medical treatment) for at least a limited period; and (b) he ought to be so detained in the interests of his own health or safety or with a view to the protection of other persons.'

For example, in <u>CD v London Borough of Croydon [2019] EWHC 2943 (Fam)</u>, the local authority brought proceedings in respect of CD, a 65-year-old man with a history of severe self-neglect. The local authority sought orders under the court's inherent jurisdiction, enabling it to gain access to CD's accommodation in order to provide appropriate care for CD and make his accommodation safe for human habitation. The judge ultimately agreed but found that there was reason to believe that CD lacked mental capacity to make decisions about his care and made orders under s.48 of the MCA. However, the judge also recorded on the order the finding that CD was a individual and so the inherent jurisdiction route was an alternative available to the local authority on the particular facts of the case.

### 2. The adult lacks mental capacity to make decisions about their self-neglect/refusal of services

A best interests decision about how to mitigate the risks of their self-neglect is then required. The first step is to gain cooperation from the adult for the proposed intervention. However, due to the nature of self-neglect, it is possible that the person will refuse to cooperate and that a degree of coercion or restraint will be required, necessitating an application to the Court of Protection. In general, the more restrictive the intervention, the greater the need to seek an order from the Court of Protection.

 $<sup>^{16}</sup>$  S.48 of the MCA: 'The court may, pending the determination of an application to it in relation to a person ("P"), make an order or give directions in respect of any matter if—(a) there is reason to believe that P lacks capacity in relation to the matter, (b)the matter is one to which its powers under this Act extend, and (c) it is in P's best interests to make the order, or give the directions, without delay.'

<sup>2020</sup> Guidance designed by Leicestershire County Council and edited by Edge Consultation to support Training