Capacity and assisted dying/assisted suicide – submission to Health and Social Care Committee's inquiry (January 2023)

Summary

In this submission, we address a number of complexities that the Committee will need to consider in relation to the place of capacity in any legislation providing for assisted dying/suicide. The main body of the submission is accompanied by an annex setting out more detailed points we suggest require consideration.[1]

Introduction

1. We are the Complex Life & Death Decisions Research Group. We are an international group concerned with life and death decision-making, with expertise in psychiatry, palliative care, bioethics, public policy and law. Members of the group have led research in life and death decision-making (particularly in relation to mental health conditions),[2] contributed to policy development, professional guidelines and law reform, as well as appearing in leading cases.

2. We have a firm commitment to a shared set of values in our research and our work; in relation to assisted dying / assisted suicide,[3] they are that:

    a. We are committed to a research-first approach;[4]
    b. We do not seek to lobby, but rather to inform;
    c. As the courts have recognised, the decision whether (and how) to change the law in this area must be one for Parliament in a democracy;
    d. We take the value of individual autonomy seriously, but we do not consider that it is the only value at play; and
    e. Research in this area needs not only disciplinary and interdisciplinary

[1] We understand from correspondence with the Committee Operations Manager that this is acceptable, given the need to balance the 3,000 word limit sought by the Committee and the detail that we wish to provide.
[2] We refer to our research throughout here where relevant, with hyperlinks to the relevant materials.
[3] As does the Health and Social Care Select Committee, we recognise that both terms are used; we use "assisted dying" in the balance of this document simply for efficiency.
[4] See, in this regard, Sleeman, K., and Owen, G. Assisted dying: we must prioritise research - The BMJ (2021).

expertise, but also viewpoint diversity.

The inquiry

3. We welcome the Health and Social Committee's inquiry, and, in particular, the breadth of the terms of reference, both thematically and geographically. In this submission, we focus on the question of "capabilities" asked by the Committee as one upon which we consider as a group that we are able to provide the Committee with research-informed expertise. However, we would be able to provide evidence in relation to the other questions asked should the Committee so wish. We are also very happy to amplify this written evidence orally should it be of assistance to the Committee.

What capabilities would a person need to be able to consent to assisted dying/assisted suicide?

4. We note that the question talks in terms of "capabilities," which includes the physical capability of the person to act. The Committee will be aware that the distinction between assisted dying and euthanasia is often drawn as being whether the person is able (physically) to carry out the relevant act, or whether another party carries out the act.[5] As we do not understand the Committee to be investigating the case for or against euthanasia (on this definition of the term), we do not address further here the physical capabilities of the person. Rather, we focus on the cognitive or mental capabilities of the person.

5. To date, all legislative proposals advanced before the Westminster Parliament (and, indeed, all other legislation either proposed or enacted in comparable jurisdictions) have been predicated upon a requirement that the person in question has the mental capacity[6] to take the decision in question. Subject to the point we identify at paragraphs 12-13 below, we anticipate that the Committee will find it difficult to imagine that any future legislation could be advanced on any other basis, as the

[5] See, for instance, Lord Neuberger in *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38 at paragraph 95.

[6] The term 'competence' is the term used in the United States, but for these purposes it has the same meaning. We use 'capacity' alone in the balance of this submission, save where we need to draw a distinction between legal and mental capacity.

linkage between capacity and autonomy is seen as so central.[7] The focus on capacity gives rise to a number of considerations, addressed in turn below.

Components of capacity

6. In England & Wales, capacity is now most usually considered by reference to the terms of the Mental Capacity Act 2005. It would in principle be possible for any legislation to include a different definition of capacity, and we note at paragraph 14 below an alternative approach which the Committee should be aware of. However, if it is the case that capacity for purposes of any legislation would be statutorily defined as being assessed by reference to the MCA 2005,[8] then it would require consideration of the following matters which we set out in headline terms here, and address in more detail in the annex:

    a. Whether and how the principles relating to capacity apply;
    b. What the decision is that the person must make, as capacity is decision-specific;
    c. What the information is that is relevant to the decision;
    d. Whether the person can make the decision;
    e. The relevance of any impairment or disturbance in the functioning of the mind or brain;
    f. The time-specificity of capacity.

What level of rigour is required in assessing capacity?

7. There is an important question of the rigour required in assessing capacity to seek assistance with dying. The Committee need to be aware that the answer to this question will depend, both systemically, and at an individual level, upon attitudes towards seeking assistance with dying. In other words, if the starting position is that

[7] See, in the medical treatment context, *Kings College Hospital NHS Foundation Trust v C & Anor* [2015] EWCOP 80.
[8] As in, for instance, the most recent Bill, proposed by Baroness Meacher (see clause 12).

seeking assistance is something unusual and risky,[9] then this would push towards a rigorous assessment of capacity in all circumstances. Conversely, if the starting position is that seeking assistance is always or sometimes (for instance in the presence of suffering) a reasonable course of action, then this would push towards a much more light touch assessment of capacity. At a minimum, therefore, we suggest that the Committee needs to be aware of the potential for unspoken or unacknowledged assumptions in this context.

Who assesses capacity?

8. The assumption in proposals for legalising assisted dying is that capacity assessment is the domain of medical professionals. However, we think that it is important that the Committee are aware that the Court of Protection (the court with oversight of the Mental Capacity Act 2005) is clear that capacity is not a purely medical matter, and that it routinely draws upon expertise from other professionals, including psychologists and social workers.[10] The Committee may well consider that the logic of the Court of Protection applies equally here, and that, given that – at least in some circumstances – the essentially existential rather than medical issues to which the assessment of capacity to seek assistance with dying give rise, there is no obvious reason why it should always be seen as a primarily medical matter.

Sufficiency of capacity

9. All frameworks of which we are aware make capacity a necessary, but not sufficient, condition, with further requirements including requirements to the effect that the decision is clear and settled, informed, and made without coercion or duress. Research conducted by members of our group has made clear just how complex the interaction between coercion and capacity can be,[11] and the High Court has developed

[9] See for research-informed guidance as to the conventional approach to take to risky decisions the relevant section of the Capacity Guide produced as part of the Mental Health and Justice Project: The situation seems risky to me - Capacity guide.

[10] See Ruck Keene, A. R., Kane, N. B., Kim, S. Y., & Owen, G. S. (2019). Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection. *International Journal of Law and Psychiatry*, *62*, 56-76.

[11] See Ariyo, K. (2022). Exploring functional and interpersonal evidence in complex capacity assessments (Doctoral dissertation, King's College London, London, UK), Ariyo being part of the contested capacity workstream on the Wellcome funded Mental Health and Justice Project.

a complex and somewhat poorly delineated jurisdiction to deal with the position where a person **has** capacity but is in some way vulnerable to coercion or duress.[12] Such coercion or duress can be overt,[13] but can also be the result of 'enmeshment.'[14]

10. However, what we want to draw the Committee's particular attention to is the work of the Canadian academic Jonas-Sebastian Beaudry, identifying a concern that capacity is, in effect, ethically insufficient. In other words, if a person perceives that they have a choice between seeking assistance in dying and receiving inadequate care, then whether they have capacity applying the test under the MCA (or any equivalent test) might be thought to be a question which is at one level entirely artificial.[15]

Capacity and those under 18

11. Legislative proposals for legalising assistance with dying have, in the English context, limited themselves to adults. However, and without advocating either for or against this position, we suggest that the Committee will no doubt wish to consider whether such is justified given that (for instance) s.8 Family Law Reform Act 1969 provides that the consent of a child over 16 serves as valid consent to medical treatment, and that there are judicially developed principles[16] to identify whether an under-16 is so-called *Gillick*[17] competent to make a decision. A justification may be the law conventionally recognises that an under 18 is "*not in all circumstances autonomous in the sense that a capacitous adult is autonomous.*"[18] But if there is any suggestion that

[12] The caselaw is summarised in guidance led on by Ruck Keene as part of the 39 Essex Chambers Mental Capacity Report editorial team: Mental Capacity Guidance Note - Inherent Jurisdiction | 39 Essex Chambers.

[13] For instance, *DL v A Local Authority & Ors* [2012] EWCA Civ 253, involving a sustained campaign of physical and emotional abuse by an adult son in relation to his elderly parents.

[14] For instance, *Southend-On-Sea Borough Council v Meyers* [2019] EWHC 399 (Fam), involving an elderly man with multiple physical disabilities putting himself in profound danger seeking to secure the wellbeing of his son.

[15] See, in particular, Beaudry, J. S. (2018). The Way Forward For Medical Aid in Dying: Protecting Deliberative Autonomy Is Not Enough. *Jonas-Sébastien Beaudry. First published in the Supreme Court Law Review, Second Series*, *85*.

[16] Precisely how clear those principles actually are may be open to question, leading the Independent Review of the Mental Health Act 1983 (to which Ruck Keene was the legal adviser) to recommend in its final report that a statutory test be developed for competence, at least in relation to admission and treatment for mental disorder (see the Report at page 174).

[17] After the decision of the House of Lords in *Gillick v West Norfolk and Wisbech AHA* [1985] UKHL 7.

[18] See *NHS Trust v X (In the matter of X (A Child) (No 2))* [2021] EWHC 65 (Fam) at paragraph 27.

a person under 18 may be able to make a request for assistance with dying, the Committee may consider that it needs to take account of the neuroscientific evidence addressing adolescent decision-making and the extent to which it maps uneasily onto conceptions of capacity contained within the MCA 2005.[19]

Validity of the concept of capacity

12. Thus far in this paper, we have identified complexities that we suggest that the Committee will be likely to wish to take into account when considering the concept of capacity in the context of assisted dying. However, we should identify that the UN Committee on the Rights of Persons with Disabilities – the treaty body for the UN Convention on the Rights of Persons with Disabilities ('CRPD') (which the UK ratified in 2009) – strongly challenges the validity of the concept of mental capacity. In its General Comment 1[20] on Article 12 (the right to legal capacity), the Committee asserted that mental capacity was not "*as commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity*."[21] Not only did the Committee attack the older models of capacity such as that based on status, i.e. that a diagnosis of an impairment automatically meant that the individual's decisions could not be regarded as legally valid, but also the functional model. The Committee considered that the functional approach to be flawed in part because "*it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right – the right to equal recognition before the law*."[22]

13. We should make clear that (1) we do not consider that the Committee's interpretation of Article 12 CRPD is, in fact, correct; and (2) and that the UK is not required to

[19] See, in particular, the work of Sarah-Jayne Blakemore, for instance Blakemore, S. J., & Choudhury, S. (2006). Development of the adolescent brain: implications for executive function and social cognition. *Journal of child psychology and psychiatry*, *47*(3-4), 296-312.
[20] Committee on the Rights of Persons with Disabilities, *General Comment No 1, Article 12: Equal recognition before the law* (UN, 2014) (General Comment 1).
[21] General Comment 1, paragraph 14.
[22] Ibid, paragraph 15.

abandon reliance upon the concept of mental capacity.[23] Further, as we are aware, the implications of this challenge for models of assisted dying which depend upon a concept of mental capacity has yet to be subject to detailed analysis.[24] However, the Committee needs to be aware that one international body would suggest that a fundamental plank of all models adopted or put forward to date is incompatible with international law.

14. In this regard, we would also draw to the Committee's attention that, from a perspective seeking to achieve CRPD compliance, the Scottish Mental Health Law Review has proposed the replacement of the concept of incapacity for purposes of relevant Scottish legislation with "*autonomous decision-making*."[25] The Review report identifies that: "[a]*n autonomous decision is one which is free from controlling influences, in other words, factors* [that] *prevent the making or communicating of an autonomous, or voluntary, decision-making it impossible for others to know the person's authentic view*."[26] The Review proceeds on the basis that "controlling influences" include:

    a. undue influence by another person or persons;
    b. the impact of any illness, disability or health condition, including a health care

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[23] Ruck Keene, A., Kane, N. B., Kim, S. Y., & Owen, G. S. (2023). Mental capacity—why look for a paradigm shift?. *Medical Law Review*.

[24] The Committee accepts the concept of assistance in dying and, indeed, euthanasia. For instance, in its concluding observations on Canada's compliance with the CRPD (CRPD/C/CAN/CO/1 (8 May 2017), it noted that it was:

> "23. […] *concerned about the adoption of legislation that provides for medical assistance in dying [which includes euthanasia], including on the grounds of disability. It is also concerned about the absence of regulations for monitoring medical assistance in dying, the absence of data to assess compliance with the procedural safeguards regarding such assistance, and the lack of sufficient support to facilitate civil society engagement with and monitoring of this practice*."

However, the Committee did not then go on to recommend that medical assistance in dying be abolished, but rather that Canada should:

> "*24 (a) Ensure persons who seek an assisted death have access to alternative courses of action and to a dignified life made possible with appropriate palliative care, disability support, home care and other social measures that support human flourishing;*
> *(b) Establish regulations pursuant to the law requiring collection and reporting of detailed information about each request and intervention for medical assistance in dying;*
> *(c) Develop a national data standard and an effective and independent mechanism to ensure that compliance with the law and regulations is strictly enforced and that no person with disability is subjected to external pressure*."

[25] See the final report, available here: Homepage | Scottish Mental Health Law Review.

[26] Review report, page 250.

crisis; and

c. the impact of any situational or environmental factors.[27]

15. The Review's recommendations have not yet been responded to by Scottish Government, so no legislative steps have been taken to develop this concept. The Committee may potentially think, however, that it is, in fact, a concept that perhaps captures rather better than the concept of mental capacity that which is usually understood to be central to requests for assistance with dying. However, considerable research would undoubtedly be required to make the concept fit for application.

Conclusion

16. As set out in the introduction, we are very happy to amplify our evidence should it be of assistance to the Committee.

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[27] Review report, page 252.

[28] Dr Kim's views are his views only and do not represent the views or policies of the NIH, DHHS, or the US government.

Annex: components of capacity and the Mental Capacity Act 2005

17. In England & Wales, capacity is now most usually considered by reference to the terms of the Mental Capacity Act 2005.[29] It would in principle be possible for any legislation to include a different definition of capacity,[30] and we note at paragraph 14 of the main submission an alternative approach which the Committee should be aware of. However, if it is the case that capacity for purposes of any legislation would be statutorily defined as being assessed by reference to the MCA 2005,[31] then it would require consideration of the matters that we set out in this section.[32]

18. Whether and how the principles relating to capacity apply. There are three principles in s.1 MCA 2005 relating to capacity, namely: a presumption of capacity; that a person cannot be held to lack capacity unless all practicable steps have been taken to support them to make their own decision; and that a person cannot be held to lack capacity merely because their decision is unwise. Each of these raise issues requiring consideration.

19. In relation to the presumption of capacity:

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[29] However, it is important to make clear that this is not because the Mental Capacity Act 2005 provides a definition of mental capacity for all purposes: as s.2 MCA 2005 makes clear, the definition of capacity that it contains applies for purposes of that Act. The test does not govern all situations where a person's legal capacity to make a decision or take an action may be in question: common law tests apply to such matters as making a will (*Banks v Goodfellow* (1870) LR 5 QB 549), making a gift (*Re Beaney* (Deceased) [1978] 2 All ER 595) or entering into a contract (*Boughton v Knight* (1873) LR 3 PD 64). *International Journal of Law and Psychiatry*, *85*, 101843.

[30] The definition of capacity in the Sexual Offences Act 2003, for instance, is not the same as the definition in the Mental Capacity Act. In relation to offences involving people with a mental disorder impeding choice, "a person is said to lack capacity to choose whether to agree to the relevant act if whether because he lacks sufficient understanding of the nature or reasonably foreseeable consequences of what is being done, or for any other reason" (see s.30(2), with equivalent provisions in ss.31-3). See also *R v Cooper* [2009] 1 WLR 1786 and Ruck Keene, A., & Enefer, A. (2022). What place has 'capacity' in the criminal law relating to sex post JB?. *International Journal of Law and Psychiatry*, *85*, 101843.

[31] As in, for instance, the most recent Bill, proposed by Baroness Meacher (see clause 12).

[32] Many would be equally relevant in deciding whether a different test could or should be adopted, and what the contents of that test should be. A helpful examination of these issues in the context of the 2010 Commission on Assisted Dying can be found in Price, A., McCormack, R., Wiseman, T., & Hotopf, M. (2014). Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying. *BMC Medical Ethics*, *15*(1), 1-11.

a. One question is whether, in effect, a presumption of capacity should be statutorily displaced given the gravity of the decision in question.[33] The second – linked – question is whether the burden of proof lies upon the person to prove that they have capacity to make the decision, or whether it lies upon the assessor to show that they do not;

b. Draft legislation such as that proposed by Baroness Meacher talks of the need for the relevant professionals to be satisfied of the person's capacity,[34] but is silent as to whether the starting point is that the person does have capacity, or that they do not;

c. If the question was being approached from the perspective of the MCA 2005, the burden would clearly lie upon the assessor, but that is because the assessor would – if the person does not have capacity – then be proceeding to take action on a best interests basis.[35] However, there could be no question – as we understand it – of a best interests decision ever being made on behalf of an incapacitated person to seek assistance in dying.[36] In the circumstances, the Committee may consider that any arguments in favour of it being for the assessor to prove incapacity fall away, and that it should always be for the person seeking assistance to prove capacity;

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[33] Framed in human rights terms, this could be framed as an aspect of the State's obligation to secure life under Article 2 ECHR. In *Mortier v Belgium* (Application No 78017/17, decision of 4 October 2022, available only in French), the court considered the compatibility of the Belgian euthanasia regime with the ECHR. At paragraph 46, the court held (in an unofficial translation) that "*the legislative framework governing acts prior to euthanasia must ensure that the patient's decision to request that his or her life be terminated is taken freely and in full knowledge of the facts. Article 2 of the Convention, which imposes on the authorities the duty to protect vulnerable persons even against acts by which they threaten their own lives, obliges the national authorities to prevent an individual from ending his life if his decision has not been taken freely and knowingly*."

[34] Clause 3(3) of Baroness Meacher's Bill.

[35] In relation to acts of care and treatment, the assessor (if they are the person doing the act) would then be protected from the liability they would otherwise incur for touching the person without consent: see s.5 MCA 2005. As Lady Hale put it in *N v ACCG* [2017] UKSC 22, Lady Hale put it in this way: "[s]*ection 5 of the 2005 Act gives a general authority, to act in relation to the care or treatment of P, to those caring for him who reasonably believe both that P lacks capacity in relation to the matter and that it will be in P's best interests for the act to be done*."

[36] Assuming that the logic of the position that only a capacitous request could be acted upon is tracked through. This would therefore fall into the same category of decisions as the 'excluded' decisions in s.27 MCA 2005 (such as consenting to marriage or sexual relations) where no substitute decision can ever be taken on behalf of the person.

20. In relation to the 'support principle,' the critical question can be framed whether the assessor should be required to take steps to support the person to make the decision, or should they simply be taking the person as they find them?

21. In relation to the 'unwise decisions' principle, there are both ethical and practical issues:

    a. The ethical issues are two-fold. First, there is the issue of whether a decision to seek assistance with dying can or should ever be seen, in and of itself, to be unwise.[37] Second, whilst a doctor must respect an unwise, but capacitous, decision to refuse life-sustaining treatment because otherwise they would be committing assault, is a doctor under an equivalent ethical obligation to respect a patient's request to seek assistance with dying whilst at the same time making what appear to be unwise decisions about their medical care, for instance refusing effective treatments?

    b. The practical issue is what is to happen where an assessor, irrespective of whatever settled high-level position may be recorded in statute, has a personal view that seeking assistance with death is necessarily unwise.

22. What the decision is that the person must make, as capacity is decision-specific (i.e. a person cannot be said simply to have or lack capacity)?[38] We note in this regard that framing the question is important at a practical level, as it will shape how the issue is considered by both those seeking assistance and those assessing capacity, but also because it will frame what information is relevant to the question.[39] As framed in the

[37] There are, linked, issues as to precisely what the concept "unwise" is supposed to capture here: see Coggon, J., & Kong, C. (2021). From best interests to better interests? Values, unwisdom and objectivity in mental capacity law. *The Cambridge Law Journal*, *80*(2), 245-273 (an output from the AHRC-funded Judging Values and Participation in Mental Capacity Law project on which Ruck Keene was a consultant).

[38] The decision-specificity of capacity was emphasised by the Supreme Court in *A Local Authority v JB* [2021] UKSC 52, the first case in which the Supreme Court considered the concept of capacity for purposes of the MCA 2005.

[39] This point was emphasised by the Supreme Court in *JB* at paragraphs 68 and 69:

> *68. As the assessment of capacity is decision-specific, the court is required to identify the correct formulation of "the matter" in respect of which it must evaluate whether P is unable to make a decision for himself* […]

terms of reference, the Committee appears to proceed on the basis that the question is whether the person can consent to assisted dying / assisted suicide. This framing sits with the idea that this is a consent-based medical process, but we note that it could equally be said that the relevant decision is not to consent, but rather to request assistance with dying.[40] Put another way, whilst, normally, a medical treatment is recommended and proposed to a person for them to consent to or refuse, a request for assistance with dying should never (we suggest) be considered a **medical** recommendation; the question is therefore not one of assessing the person's capacity to accept or refuse a proposed medical treatment. Rather, it is one of their capacity to make a request for assistance with dying.

23. What the information is that is relevant to the decision. We would emphasise that the choice of what information is relevant (and, almost – if not as – important, what information is **not** relevant) is a choice with significant implications.[41] Put crudely, the less information relating to the decision the person needs to be able to understand, retain, use and weigh, the more likely it is that they will have capacity to make the decision; conversely, the more that they need to be able to process, the less likely it is that they will have capacity. In this regard, it is important to draw to the Committee's attention that there has been a dearth of research on what information is required to be able to make a decision to seek assisted dying,[42] (unsurprisingly) a dearth of case-law considering the question in the English context,[43] and little sustained engagement by legislatures with this issue. The Committee may think that

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69. The correct formulation of "the matter" then leads to a requirement to identify "the information relevant to the decision" under section 3(1)(a) […]

[40] The decision is framed in Baroness Meacher's Bill as "the decision to end their own life" (clause 3(3)).

[41] In *A Local Authority v JB* [2021] UKSC 52, it was the identification of specific information as **legally** relevant which made the difference between the person being found (at first instance) to have capacity to decide to engage in sexual relations, and them being found (at Supreme Court) level not to have such capacity.

[42] For instance, a paper examining capacity (Shaw, D., Trachsel, M., & Elger, B. (2018). Assessment of decision-making capacity in patients requesting assisted suicide. *The British Journal of Psychiatry*, *213*(1), 393-395) did not examine this question at all. Suggestions were advanced in Stewart, C., Peisah, C., & Draper, B. (2011). A test for mental capacity to request assisted suicide. *Journal of Medical Ethics*, *37*(1), 34-39.

[43] The decision of Hedley J in *Local Authority v Z* [2004] EWHC 2817 concerning the capacity of a woman to seek to travel to Dignitas for purposes of ending her life comes closest, but did not identify the information that the court-appointed expert (whose conclusions the court accepted) had considered in their assessment of capacity.

there are some analogies to be drawn to the information that may be relevant to a person's decision (1) to take their own life;[44] and/or (2) to refuse life-sustaining treatment, but even if there are, we suggest that there is a need for this question to be the subject of detailed consideration.[45]

24. Whether the person can make the decision. There is a statutory definition in the MCA 2005 of what it means to be able to make a decision,[46] namely to be able to understand the relevant information, retain it, use and weigh it, and to be able to communicate the decision. Whether a particular person can make a decision (to seek or to consent to assisted dying, or whichever other formulation is chosen) is first and foremost going to be a matter for the assessor to consider.[47] However, we need to draw to the Committee's attention two matters:

    a. The risk that capacity assessment is simply done on a global basis, rather than by actually analysing the criteria; [48]

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[44] An area of very considerable difficulty: see the 'shedinar' conversation between Ruck Keene and Dr Chloe Beale: Suicide and the (mis)use of capacity – in conversation with Dr Chloe Beale – Mental Capacity Law and Policy

[45] One approach to such consideration would be by way of the "policy lab" approach pioneered by the King's Policy Institute, which was deployed, for instance, in the context of seeking to identifying "just" ways in which to resolve uncertainty in the mental health and capacity sphere: see Pollit A., Benson R., & Ruck Keene, A. A "just" approach to uncertainty in mental health and capacity practice and policy Findings from a Policy Lab (May 2022).

[46] Section 3 MCA 2005.

[47] The Committee may well wish to have regard to the PhD thesis of Dr Annabel Price: *Mental capacity assessment for terminally ill adults requesting physician assisted suicide: a qualitative study using a grounded theory approach* (2016), in which she specifically sought to answer the question of how doctors, including psychiatrists would go about determining capacity for terminally adults requesting physician assisted suicide were the practice legal in England and Wales. Her conclusion (at page 210) was that:

> *for a theoretically sampled group of doctors in England and Wales, knowing the patient was a core condition of the process of assessment of capacity both generally and for the decision to request physician assisted suicide. In the specific situation of assessment of capacity for physician assisted suicide, knowing the patient was found to be a contextual phenomenon impacted upon by a number of elements including the doctors' perspectives on legalisation of assisted suicide, their frame of reference (professional, personal or moral), their views on the meaning of suffering and the dying process and their conceptualisation of mental capacity (particularly cognitive vs broad, and whether their conceptualisation was in accordance with the principles of the Mental Capacity Act 2005.*

[48] For instance, in an analysis of capacity evaluations of psychiatric patients requesting assisted dying in the Netherlands, Kim and others identified that in over half of the cases, there was a simple global assertion of capacity, without reference to specific capacity criteria: see Doernberg, S. N., Peteet, J. R., & Kim, S. Y. (2016). Capacity evaluations of psychiatric patients requesting assisted death in the Netherlands. *Psychosomatics*, *57*(6), 556-565.

b. That 15 years after the MCA 2005 came into force, the question (in particular) what it means to 'use and weigh' information is one that still causes considerable challenges in application.[49]

25. Separately in relation to this issue, the Committee will also want to consider whether and how the 'communication' limb of the capacity test is relevant. This was designed to address either (1) the situation where the person is unconscious; or (2) rare conditions such as locked-in syndrome "*where a conscious patient may be known to retain a level of cognitive functioning but the brain may be completely unable to communicate with the body or with the outside world*."[50] In effect, it is a limb of the test designed to provide a 'work around' for the fact that it is simply impossible to tell whether, in fact, the person is able to make a decision. Given that there will be no situations in which a best interests decision could be made on behalf of a person to seek assistance with dying, we suggest that there is ambiguity about whether the communication limb serves any purpose – and, linked, what, if any, standard of proof should apply in deciding whether a person communicating by a non-conventional means is doing so sufficiently reliably.

26. Finally, the Committee will also want to consider what steps can or could be taken to secure against the risk that capacity determinations do not appropriately take account of protected characteristics. There is limited research relating to the impact of race upon capacity assessment,[51] but far less research than (for instance) in

[49] These challenges were examined by Owen, Ruck Keene and Kim (together with Dr Nuala Kane) on the contested capacity workstream of the Wellcome funded Mental Health and Justice Project: see, in particular, Ruck Keene, A. R., Kane, N. B., Kim, S. Y., & Owen, G. S. (2019). Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection. *International journal of law and psychiatry*, *62*, 56-76; Kane, N. B., Keene, A. R., Owen, G. S., & Kim, S. Y. (2021). Applying decision-making capacity criteria in practice: A content analysis of court judgments. *PloS one*, *16*(2), e0246521; and Kim, S. Y., Kane, N. B., Keene, A. R., & Owen, G. S. (2022). Broad concepts and messy realities: optimising the application of mental capacity criteria. *Journal of Medical Ethics*, *48*(11), 838-844.

[50] See the Law Commission report on Mental Incapacity (Law Com No 231, 1995), the work leading ultimately to the MCA 2005, at paragraph 3.13.

[51] Owen, G. S., David, A. S., Richardson, G., Szmukler, G., Hayward, P., & Hotopf, M. (2009). Mental capacity, diagnosis and insight in psychiatric in-patients: a cross-sectional study. *Psychological medicine*, *39*(8), 1389-1398.

relation to the application of the Mental Health Act 1983.[52] There is also very little, if any, research of which we are aware on the effect of gender,[53] age or the assessor's perception of physical disability upon capacity determination. The Committee may well consider that these are all areas which require further consideration if (in effect) assisted dying is to be offered as a treatment option.

27. The relevance of any impairment or disturbance in the functioning of the mind or brain. In situations governed by the MCA 2005, a conclusion that a person cannot make the decision in question (i.e. they cannot understand, retain, use or weigh the relevant information, or communicate their decision) can only lead to a conclusion that they lack capacity to take the relevant decision if they cannot do so because of an impairment of or disturbance in the functioning of their mind or brain.[54] However, the requirement to satisfy the so-called 'causative nexus' is problematic in the context of assisted dying. If a person cannot make a decision to seek assisted dying, then it might be thought problematic to say that they nonetheless have capacity to seek assistance because their inability (for instance) to use or weigh the relevant information cannot be linked to a specific impairment or disturbance in the functioning of their mind or brain. In other words, it might be thought problematic that a conclusion has to be reached that the person **has** capacity to seek assistance because their difficulty processing the relevant information results from strong interpersonal or social pressure, rather than (say) the effect of dementia.

28. In addition, we suggest that the Committee will want to consider carefully the effect of conditions such as depression on decision-making. Research conducted by a

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[52] For a consideration of whether and how capacity assessment may be affected by a mismatch (in effect) between the backgrounds of the assessor and the assessed, the Committee may find helpful this 'shedinar' discussion between Ruck Keene and Dr Shubulade Smith: Race, culture and capacity – in conversation with Dr Lade Smith CBE – Mental Capacity Law and Policy.

[53] Particularly relevant given the difference between the gender distribution in suicide and in suicide attempts (the so-called suicide 'gender paradox'); see Nicolini, M. E., Gastmans, C., & Kim, S. Y. (2022). Psychiatric euthanasia, suicide and the role of gender. *The British Journal of Psychiatry*, *220*(1), 10-13.

[54] Section 2(1) MCA 2005. As Macdonald J identified in *Kings College Hospital NHS Foundation Trust v C* [2015] EWCOP 80 (at paragraph 31) "[t]*he question* […] i*s not whether the person's ability to take the decision is impaired by the impairment of, or disturbance in the functioning of, the mind or brain but rather whether the person is rendered unable to make the decision by reason thereof (see Re SB (A Patient: Capacity to Consent to Termination) [2013] EWHC 1417 (COP) at [38]).*"

member of the group has indicated just how complex it can be to identify and assess capacity in the presence of depression.[55] This complexity will be magnified when the relevant information for the decision relates to ending one's life. At a minimum, we suggest, the Committee will want to consider what steps can and should be taken to ensure that conditions such as depression are identified and addressed in the context of capacity assessment for assisted in dying.

29. The time-specificity of capacity. For purposes of the MCA 2005, capacity is both decision- and time-specific. This gives rise to two issues requiring consideration:

    a. The impact of degenerative cognitive conditions such as dementia. Put shortly – does the person have to have capacity to seek assistance at the point of such formal assessment(s) as are likely to form the centrepiece of any legislation **and** at the point when assistance is rendered, or does it suffice that they have capacity solely at the former point?[56] And if the former, would this open the way to advance requests for assistance in dying?[57]

    b. How to address the position of a person with fluctuating capacity, for instance bipolar disorder? For purposes of the MCA 2005, the statutory guidance is, in effect, to take the person at their best, as an aspect of the 'support' principle.[58] Would such be an acceptable approach in this context? And, if not, would it be discriminatory against those with conditions which give rise to fluctuating capacity to exclude them from accessing any legislative scheme that is established?

[55] Owen, G. S., Freyenhagen, F., Hotopf, M., & Martin, W. (2015). Temporal inabilities and decision-making capacity in depression. *Phenomenology and the Cognitive Sciences*, *14*(1), 163-182.a

[56] The Committee will note in this regard that Baroness Meacher's Bill appeared to proceed on the basis that it would suffice to have capacity at the point of formal assessment.

[57] The complexities of such requests are vividly illustrated by the Dutch experience: see Miller, D. G., Dresser, R., & Kim, S. Y. (2019). Advance euthanasia directives: a controversial case and its ethical implications. *Journal of Medical Ethics*, *45*(2), 84-89.

[58] See paragraphs 3.12-3.16 and 4.26 of the Mental Capacity Act Code of Practice.