The University of Manchester
Institute for Collaborative
Research on Ageing

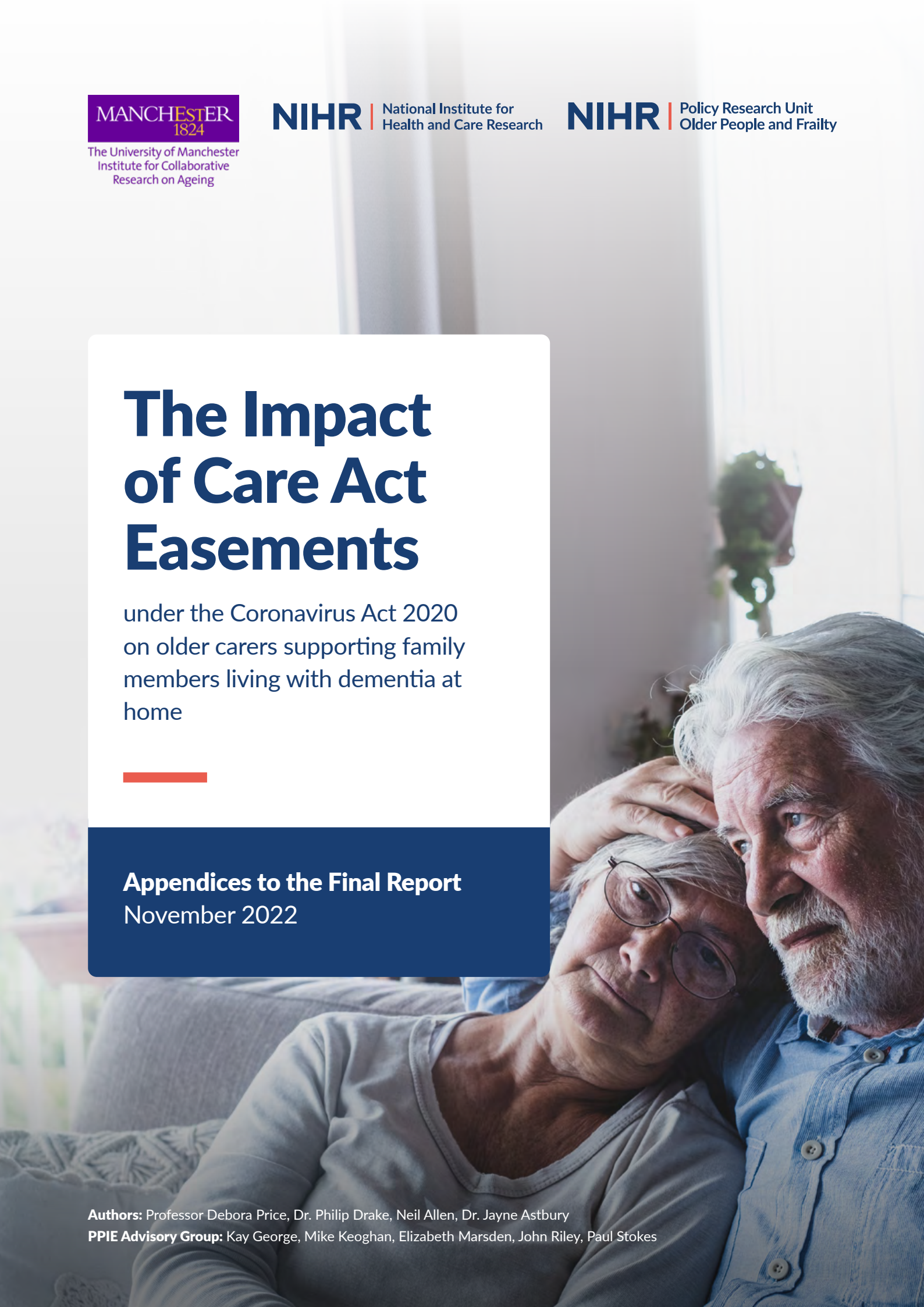
NIHR | National Institute for Health and Care Research

NIHR | Policy Research Unit Older People and Frailty

The Impact of Care Act Easements

under the Coronavirus Act 2020 on older carers supporting family members living with dementia at home

Appendices to the Final Report
November 2022



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The report and related documents are available at:
https://www.opfpru.nihr.ac.uk/our-research/projects/the-impact-of-care-act-easements

This document can be downloaded from:
https://documents.manchester.ac.uk/display.aspx?DocID=64488

Appendix 1: Extracts from Legislation, Guidance and Ethical Framework

Most relevant easements

Coronavirus Act 2020 Schedule 12:

- para.2(1)(a)-(b) disapplied duties under Care Act 2014 ss.9–10 (to assess needs)
- para.2(1)(d) disapplied duties under Care Act 2014 ss.12(3)-(4) (to give written records of assessments)
- para.2(2) disapplied duties under Care Act 2014 s.13 (to determine eligibility)
- para.3 disapplied the duties in Care Act 2014 s.17 (to financially assess)
- para.4 disapplied duties under Care Act s.18 (to meet needs for care and support)
- para.6 disapplied duty under Care Act s.20 (to meet a carer's needs for support)
- para.8 disapplied duty under Care Act s.30 (choice of preferred accommodation)
- para.11 disapplied duties under Care Act 2014 ss.24, 25, and 27 (to preparing and reviewing care and/or support plans)

Coronavirus Act 2020 Schedule 12

Local authority care and support

PART 1

Powers and duties of local authorities in England

Introductory

1 (1) In this Part of this Schedule "CA 2014" means the Care Act 2014.

(2) Expressions used in this Part of this Schedule and in Part 1 of CA 2014 have the same meaning in this Part of this Schedule as in Part 1 of that Act.

Assessing needs for care and support

2 (1) A local authority does not have to comply with any duties imposed by the following provisions—

(a) section 9 of CA 2014 (assessment of an adult's needs for care and support);

(b) section 10 of that Act (assessment of a carer's needs for support);

(c) any regulations made under section 12(1) or (2) of that Act (further provision about assessments under section 9 or 10);

(d)section 12(3) and (4) of that Act (duties to give written records of assessments);

(and accordingly section 11 of that Act (refusal of assessment) does not apply).

(2) A local authority does not have to comply with any duties imposed by section 13 of CA 2014 (determination of whether needs meet the eligibility criteria) or any regulations made under that section.

(3) A local authority does not have to comply with any duties imposed by the following provisions—

(a)sections 58 and 59 of CA 2014 (assessment of a child's needs for care and support);

(b) sections 60 and 61 of that Act (assessment of a child's carer's needs for support);

(c) sections 63 and 64 of that Act (assessment of a young carer's needs for support);

(d) any regulations made under section 65(1) of that Act (further provision about assessments under sections 58 to 64).

(4) Nothing in this paragraph prevents a local authority from carrying out any assessment, or making any determination, it considers appropriate for the purposes of exercising its functions under section 18, 19, 20 or 62 of CA 2014 (as modified by paragraphs 4 to 6 and 9 of this Schedule).

Assessment of financial resources

3 (1) A local authority does not have to comply with any duties imposed by section 17 of CA 2014 (assessment of financial resources). This is subject to sub-paragraph (2).

(2) A local authority may not make a charge under section 14 of CA 2014 for meeting any needs under section 18, 19, 20 or 62 of that Act during a period for which paragraph 4, 5, 6 or (as the case may be) 9 of this Schedule has effect without having carried out an assessment under section 17 of that Act.

(3) The requirement under sub-paragraph (2) to carry out an assessment under section 17 of CA 2014 applies whether or not the authority has made a determination under section 13(1) of that Act.

Duties and powers to meet needs for care and support

4 Section 18 of CA 2014 (duty to meet needs for care and support) has effect as if for subsection (1) there were substituted—

"(1) A local authority must meet an adult's needs for care and support if—

(a) the adult is ordinarily resident in the authority's area or is present in its area but of no settled residence,

(b) the authority considers that it is necessary to meet those needs for the purpose of avoiding a breach of the adult's Convention rights, and

(c) there is no charge under section 14 for meeting the needs or, in so far as there is, condition 1, 2 or 3 is met.

In this subsection "Convention rights" has the same meaning as in the Human Rights Act 1998."

5 Section 19 of CA 2014 (power to meet needs for care and support) has effect as if there were omitted—

(a) the reference in subsection (1) to having carried out a needs assessment and a financial assessment;

(b) the reference in subsection (2) to having made a determination under section 13(1) of that Act, and the words "which meet the eligibility criteria";

(c) the reference in subsection (3) to having not yet carried out a needs assessment or made a determination under section 13(1) of that Act.

6 In section 20 of CA 2014 (duty and power to meet a carer's needs for support), subsection (1) has effect as if—

(a) the words ", having made a determination under section 13(1)," and "which meet the eligibility criteria" were omitted;

(b) after paragraph (a) there were inserted—

"(aa) the authority considers that it is necessary to meet those needs for the purpose of avoiding a breach of the carer's Convention rights,";

(c) at the end there were inserted—

"In this subsection "Convention rights" has the same meaning as in the Human Rights Act 1998."

7 (1) For the purposes of sections 18(6) and 20(9) of CA 2014 (meaning of references to there being no charge for meeting needs), a local authority that decides not to carry out an assessment under section 17 of that Act as a result of paragraph 3(1) above is to be treated as having decided not to make a charge under section 14 of that Act (but see paragraph 10 below).

(2) But the duty under section 18 or 20(1) of CA 2014 does not apply to a local authority if—

(a)the authority notifies the relevant person that it may make a charge for meeting needs under that section, and

(b) the relevant person asks the authority not to meet those needs.

(3) In sub-paragraph (2) "the relevant person" means—

(a) the person who would be liable to pay any such charge, or

(b) in a case where—

(i) the authority would be meeting the needs of an adult under section 18 of CA 2014, and

(ii) the adult lacks capacity to arrange for the provision of care and support, a person who is authorised under the Mental Capacity Act 2005 to arrange for such provision or is otherwise in a position to do so on the adult's behalf.

8 A local authority does not have to comply with any duties imposed by the following provisions—

(a) any regulations made under section 30 of CA 2014 (cases where adult expresses preference for particular accommodation);

(b) section 47(2) of that Act (duty to prevent or mitigate loss or damage to property of adults being cared for away from home).

9 Section 62 of CA 2014 (power to meet child's carer's needs for support) has effect as if the reference in subsection (1) to having carried out a child's carer's assessment were omitted.

Charging for meeting needs during emergency period

10 (1) This paragraph applies where—

(a)at any time during an emergency period, a local authority begins to meet needs under section 18, 19, 20 or 62 of CA 2014,

(b) at that time, the authority would have been entitled to make a charge under section 14 of that Act for meeting any of those needs, but

(c) the authority decided not to carry out an assessment under section 17 of that Act before beginning to meet those needs.

In this paragraph "emergency period", in relation to section 18, 19, 20 or 62 of CA 2014, means a period for which paragraph 4, 5, 6 or (as the case may be) 9 of this Schedule has effect.

(2) The local authority is not prevented by that decision from subsequently carrying out an assessment under section 17 of CA 2014 (whether during or after the emergency period) and deciding to make a charge for meeting those needs during that period; and nothing in that section is to be taken to prevent the authority from carrying out such an assessment, even though the authority has already begun to meet, or has met, those needs.

(3) In so far as there is any charge for meeting any needs under section 18 or 19(2) of CA 2014 during the emergency period, the fact that condition 1, 2 or 3 in section 18 of that Act is not met at the time of the making of the charge does not affect anything already done under section 18 or (as the case may be) 19(2) of that Act.

(4) In so far as there is any charge for meeting any needs under section 20(1) of CA 2014 during the emergency period, the fact that condition 1, 2, 3 or 4 in that section is not met at the time of the making of the charge does not affect anything already done under that section.

Care and support plans etc

11 A local authority does not have to comply with any duties imposed by the following provisions of CA 2014—

(a) section 24 (duty to prepare care and support plan or support plan, etc);

(b) section 25 (duties relating to plans);

(c) section 27(1), (4), (4A) and (5) (duty to review plans, etc).

The reference in paragraph (c) to subsection (4A) of section 27 of CA 2014 is to the subsection treated as inserted by regulation 11 of the Care and Support (Children's Carers) Regulations 2015 (S.I. 2015/305).

Continuity of care and support when person moves

12 A local authority does not have to comply with any duties imposed by the following provisions of CA 2014—

(a) section 37 (duties of notification, assessment, etc when a person moves);

(b) section 38 (case where assessments not complete on day of move).

13 (1) This paragraph applies where—

(a) paragraph 12 has had effect for any period ("the emergency period"), and

(b) the emergency period has ended.

(2) Section 37 of CA 2014 has effect subject to the modifications in sub-paragraphs (3) to (5).

(3) In subsections (1) and (2)—

(a) any reference to notifying a local authority that an adult intends to move to the area of that authority includes, in the case of an adult who moved to the area of a local authority during the emergency period, a reference to notifying that authority that the adult has moved to that area, and

(b) where a local authority is notified that an adult has moved to the authority's area by virtue of paragraph (a), the condition in subsection (1)(c) or (as the case may be) (2)(c) is to be disregarded (and accordingly the requirement imposed by subsection (4)(b) does not apply).

(4) In subsection (3)—

(a) the reference to notifying a local authority that an adult intends to move out of accommodation but to remain in the authority's area includes, in the case of an adult who moved out of accommodation in the area of a local authority during the emergency period, a reference to notifying that authority that the adult has moved out of the accommodation but has remained in that area, and

(b) where a local authority is notified that an adult has moved out of accommodation by virtue of paragraph (a), the condition in subsection (3)(c) is to be disregarded (and accordingly the requirement imposed by subsection (4)(b) does not apply).

(5) In a case where subsection (4)(b) does not apply by virtue of sub-paragraph (3)(b) or (4)(b), subsection (5) has effect as if the reference to having received the notification under subsection (4)(b) were omitted.

(6) The reference in section 38(1) of CA 2014 to the day of the intended move is, in the case of an adult who moved as mentioned in section 37(1)(b), (2)(b) or (3)(b) of that Act during the emergency period, to be read as a reference to the day on which that period ended.

Discharge of hospital patients with care and support needs

14 In Schedule 3 to CA 2014 (discharge of hospital patients with care and support needs), paragraph 3 has effect as if for sub-paragraph (1) there were substituted—

"(1) The relevant authority, having received an assessment notice, must inform the NHS body responsible for the patient—

(a) whether the patient has needs for care and support,

(b) (where applicable) whether a carer has needs for support,

(c) which (if any) of those needs the authority plans to meet, and

(d) how the authority plans to meet those needs."

Transition for children to adult care and support

15 A local authority does not have to comply with any duties imposed by—

(a) section 2A(2) to (4) or (6) of the Chronically Sick and Disabled Persons Act 1970 (welfare services: transition for children to adult care and support), or

(b) section 17ZH(2) to (4) or (6) of the Children Act 1989 (section 17 services: transition for children to adult care and support).

Duties arising before commencement

16 (1) A provision of this Part of this Schedule that provides that a local authority does not have to comply with a relevant duty, or modifies a relevant duty of a local authority, applies in relation to duties arising before the commencement day as it applies in relation to duties arising on or after that day.

(2) In sub-paragraph (1)—

"the commencement day", in relation to a provision of this Part of this Schedule, means—

(a) the day on which that provision comes into force, or

(b) where on any day the operation of the provision is revived by regulations under section 88(3), that day;

"relevant duty" means a duty under—

(a) Part 1 of CA 2014,

(b) section 2A(2) to (4) or (6) of the Chronically Sick and Disabled Persons Act 1970, or

(c) section 17ZH(2) to (4) or (6) of the Children Act 1989.

Period within which assessments may be carried out

17 (1) Sub-paragraph (2) applies where—

(a) any provision of paragraph 2 or 12 has had effect for any period, and

(b) that period has ended.

(2) In determining for the purposes of any proceedings whether a local authority has complied with its duty to carry out a relevant assessment within a reasonable period, a court must take into account (among other things) the following factors—

(a) the length of any period for which any provision of paragraph 2 or 12 had effect, and

(b) the number of relevant assessments which need to be carried out by the local authority following the end of any such period.

(3) In this paragraph "relevant assessment" means—

(a) a needs assessment under section 9 of CA 2014;

(b) a carer's assessment under section 10 of that Act;

(c) a determination under section 13(1) of that Act;

(d) an assessment under section 37(6) of that Act;

(e) a child's needs assessment under section 58 of that Act;

(f) a child's carer's assessment under section 60 of that Act;

(g) a young carer's assessment under section 63 of that Act.

Guidance

18 (1) The Secretary of State may issue guidance about how local authorities are to exercise functions under any of the following enactments in consequence of the provision made by this Part of this Schedule—

(a) Part 1 of CA 2014;

(b) section 2 of the Chronically Sick and Disabled Persons Act 1970;

(c) section 17 of the Children Act 1989.

(2) A local authority must have regard to any guidance issued under this paragraph.

(3) A local authority must comply with such guidance issued under this paragraph as the Secretary of State directs.

(4) The Secretary of State—

(a) may from time to time revise any guidance issued under this paragraph;

(b) may vary or revoke a direction made under sub-paragraph (3).

(5) A local authority may disregard any guidance under section 7 of the Local Authority Social Services Act 1970 or section 78 of CA 2014, so far as it is inconsistent with guidance issued under this paragraph.

Care Act 2014

Easement stages 3 and 4 meant a local authority did not have to comply with certain statutory duties including ss.9-10 and regulations (cared-for person and carer's needs assessments), 12 (written records of assessments), 13 and regulations (determination of eligible needs), 17 (financial assessment), 18 (meeting cared-for person's eligible needs), 20 (meeting carer's eligible needs), 30+regs (choice of accommodation), 24-25 and 27 (preparing and reviewing care and/or support plans)

9 Assessment of an adult's needs for care and support

(1) Where it appears to a local authority that an adult may have needs for care and support, the authority must assess—

(a) whether the adult does have needs for care and support, and

(b) if the adult does, what those needs are.

(2) An assessment under subsection (1) is referred to in this Part as a "needs assessment".

(3) The duty to carry out a needs assessment applies regardless of the authority's view of—

(a) the level of the adult's needs for care and support, or

(b) the level of the adult's financial resources.

(4) A needs assessment must include an assessment of—

(a) the impact of the adult's needs for care and support on the matters specified in section 1(2),

(b) the outcomes that the adult wishes to achieve in day-to-day life, and

(c) whether, and if so to what extent, the provision of care and support could contribute to the achievement of those outcomes.

(5) A local authority, in carrying out a needs assessment, must involve—

(a) the adult,

(b) any carer that the adult has, and

(c) any person whom the adult asks the authority to involve or, where the adult lacks capacity to ask the authority to do that, any person who appears to the authority to be interested in the adult's welfare.

(6) When carrying out a needs assessment, a local authority must also consider—

(a) whether, and if so to what extent, matters other than the provision of care and support could contribute to the achievement of the outcomes that the adult wishes to achieve in day-to-day life, and

(b) whether the adult would benefit from the provision of anything under section 2 or 4 or of anything which might be available in the community.

(7) This section is subject to section 11(1) to (4) (refusal by adult of assessment).

10 Assessment of a carer's needs for support

(1) Where it appears to a local authority that a carer may have needs for support (whether currently or in the future), the authority must assess—

(a) whether the carer does have needs for support (or is likely to do so in the future), and

(b) if the carer does, what those needs are (or are likely to be in the future).

(2) An assessment under subsection (1) is referred to in this Part as a "carer's assessment" .

(3) "Carer" means an adult who provides or intends to provide care for another adult (an "adult needing care"); but see subsections (9) and (10).

(4) The duty to carry out a carer's assessment applies regardless of the authority's view of—

(a) the level of the carer's needs for support, or

(b) the level of the carer's financial resources or of those of the adult needing care.

(5) A carer's assessment must include an assessment of—

(a) whether the carer is able, and is likely to continue to be able, to provide care for the adult needing care,

(b) whether the carer is willing, and is likely to continue to be willing, to do so,

(c) the impact of the carer's needs for support on the matters specified in section 1(2),

(d) the outcomes that the carer wishes to achieve in day-to-day life, and

(e) whether, and if so to what extent, the provision of support could contribute to the achievement of those outcomes.

(6) A local authority, in carrying out a carer's assessment, must have regard to—

(a) whether the carer works or wishes to do so, and

(b) whether the carer is participating in or wishes to participate in education, training or recreation.

(7) A local authority, in carrying out a carer's assessment, must involve—

(a) the carer, and

(b) any person whom the carer asks the authority to involve.

(8) When carrying out a carer's assessment, a local authority must also consider—

(a) whether, and if so to what extent, matters other than the provision of support could contribute to the achievement of the outcomes that the carer wishes to achieve in day-to-day life, and

(b) whether the carer would benefit from the provision of anything under section 2 or 4 or of anything which might be available in the community.

(9) An adult is not to be regarded as a carer if the adult provides or intends to provide care—

(a) under or by virtue of a contract, or

(b) as voluntary work.

(10) But in a case where the local authority considers that the relationship between the adult needing care and the adult providing or intending to provide care is such that it would be appropriate for the latter to be regarded as a carer, that adult is to be regarded as such (and subsection (9) is therefore to be ignored in that case).

(11) The references in this section to providing care include a reference to providing practical or emotional support.

(12) This section is subject to section 11(5) to (7) (refusal by carer of assessment).

12 Assessments under sections 9 and 10: further provision

(1) Regulations must make further provision about carrying out a needs or carer's assessment; the regulations may, in particular—

(a) require the local authority, in carrying out the assessment, to have regard to the needs of the family of the adult to whom the assessment relates;

(b) specify other matters to which the local authority must have regard in carrying out the assessment (including, in particular, the matters to which it must have regard in seeking to ensure that the assessment is carried out in an appropriate and proportionate manner);

(c) specify steps that the local authority must take for the purpose of ensuring that the assessment is carried out in an appropriate and proportionate manner;

(d) specify circumstances in which the assessment may or must be carried out by a person (whether or not an officer of the authority) who has expertise in a specified matter or is of such other description as is specified, jointly with or on behalf of the local authority;

(e) specify circumstances in which the adult to whom the assessment relates may carry out the assessment jointly with the local authority;

(f) specify circumstances in which the local authority must, before carrying out the assessment or when doing so, consult a person who has expertise in a specified matter or is of such other description as is specified;

(g) specify circumstances in which the local authority must refer the adult concerned for an assessment of eligibility for NHS continuing healthcare.

(2) The regulations may include provision for facilitating the carrying out of a needs or carer's assessment in circumstances specified under subsection (1)(d) or (e); they may, for example, give the local authority power to provide the person carrying out the assessment—

(a) in the case of a needs assessment, with information about the adult to whom the assessment relates;

(b) in the case of a carer's assessment, with information about the carer to whom the assessment relates and about the adult needing care;

(c) in either case, with whatever resources, or with access to whatever facilities, the authority thinks will be required to carry out the assessment.

(3) The local authority must give a written record of a needs assessment to—

(a) the adult to whom the assessment relates,

(b) any carer that the adult has, if the adult asks the authority to do so, and

(c) any other person to whom the adult asks the authority to give a copy.

(4) The local authority must give a written record of a carer's assessment to—

(a) the carer to whom the assessment relates,

(b) the adult needing care, if the carer asks the authority to do so, and

(c) any other person to whom the carer asks the authority to give a copy.

(5) A local authority may combine a needs or carer's assessment with an assessment it is carrying out (whether or not under this Part) in relation to another person only if the adult to whom the needs or carer's assessment relates agrees and—

(a) where the combination would include an assessment relating to another adult, that other adult agrees;

(b) where the combination would include an assessment relating to a child (including a young carer), the consent condition is met in relation to the child.

(6) The consent condition is met in relation to a child if—

(a) the child has capacity or is competent to agree to the assessments being combined and does so agree, or

(b) the child lacks capacity or is not competent so to agree but the local authority is satisfied that combining the assessments would be in the child's best interests.

(7) Where a local authority is carrying out a needs or carer's assessment, and there is some other assessment being or about to be carried out in relation to the adult to whom the assessment relates or in relation to a relevant person, the local authority may carry out that other assessment—

(a) on behalf of or jointly with the body responsible for carrying it out, or

(b) if that body has arranged to carry out the other assessment jointly with another person, jointly with that body and the other person.

(8) A reference to a needs or carer's assessment includes a reference to a needs or carer's assessment (as the case may be) which forms part of a combined assessment under subsection (5).

(9) A reference to an assessment includes a reference to part of an assessment.

(10) "NHS continuing health care" is to be construed in accordance with standing rules under section 6E of the National Health Service Act 2006.

(11) A person is a "relevant person" , in relation to a needs or carer's assessment, if it would be reasonable to combine an assessment relating to that person with the needs or carer's assessment (as mentioned in subsection (5)).

13 The eligibility criteria

(1) Where a local authority is satisfied on the basis of a needs or carer's assessment that an adult has needs for care and support or that a carer has needs for support, it must determine whether any of the needs meet the eligibility criteria (see subsection (7)).

(2) Having made a determination under subsection (1), the local authority must give the adult concerned a written record of the determination and the reasons for it.

(3) Where at least some of an adult's needs for care and support meet the eligibility criteria, the local authority must—

(a) consider what could be done to meet those needs that do,

(b) ascertain whether the adult wants to have those needs met by the local authority in accordance with this Part, and

(c) establish whether the adult is ordinarily resident in the local authority's area.

(4) Where at least some of a carer's needs for support meet the eligibility criteria, the local authority must—

(a) consider what could be done to meet those needs that do, and

(b) establish whether the adult needing care is ordinarily resident in the local authority's area.

(5) Where none of the needs of the adult concerned meet the eligibility criteria, the local authority must give him or her written advice and information about—

(a) what can be done to meet or reduce the needs;

(b) what can be done to prevent or delay the development of needs for care and support, or the development of needs for support, in the future.

(6) Regulations may make provision about the making of the determination under subsection (1).

(7) Needs meet the eligibility criteria if—

(a) they are of a description specified in regulations, or

(b) they form part of a combination of needs of a description so specified.

(8) The regulations may, in particular, describe needs by reference to—

(a) the effect that the needs have on the adult concerned;

(b) the adult's circumstances.

17 Assessment of financial resources

(1) Where a local authority, having made a determination under section 13(1), thinks that, if it were to meet an adult's needs for care and support, it would charge the adult under section 14(1) for meeting at least some of the needs, it must assess—

(a) the level of the adult's financial resources, and

(b) the amount (if any) which the adult would be likely to be able to pay towards the cost of meeting the needs for care and support.

(2) Where a local authority thinks that, in meeting an adult's needs for care and support, it would make a charge under section 15(7), it must assess—

(a) the level of the adult's financial resources, and

(b) the amount (if any) which the adult would be likely to be able to pay towards the amount attributable to the adult's daily living costs.

(3) Where a local authority, having made a determination under section 13(1), thinks that, if it were to meet a carer's needs for support, it would charge the carer under section 14(1) for meeting at least some of the needs, it must assess—

(a) the level of the carer's financial resources, and

(b) the amount (if any) which the carer would be likely to be able to pay towards the cost of meeting the needs for support.

(4) Where a local authority, having made a determination under section 13(1), thinks that, if it were to meet a carer's needs for support, it would charge the adult needing care under section 14(1) for meeting at least some of the needs, it must assess—

(a) the level of the financial resources of the adult needing care, and

(b) the amount (if any) which the adult needing care would be likely to be able to pay towards the cost of meeting the carer's needs for support.

(5) An assessment under this section is referred to in this Part as a "financial assessment" .

(6) A local authority, having carried out a financial assessment, must give a written record of the assessment to the adult to whom it relates.

(7) Regulations must make provision about the carrying out of a financial assessment.

(8) The regulations must make provision as to cases or circumstances in which, if the financial resources of an adult who has needs for care and support (whether in terms of income, capital or a combination of both) exceed a specified level, a local authority is not permitted to, or may (but need not)—

(a) in a case where the adult's accrued costs do not exceed the cap on care costs, pay towards the cost of the provision of care and support for the adult;

(b) in a case where the adult's accrued costs exceed the cap on care costs, pay towards the amount attributable to the adult's daily living costs.

(9) The regulations must make provision as to cases or circumstances in which, if the financial resources of a carer who has needs for support or of the adult needing care (whether in terms of income, capital or a combination of both) exceed a specified level, a local authority is not permitted to, or may (but need not), pay towards the cost of the provision of support for the carer.

(10) The level specified for the purposes of subsections (8) and (9) is referred to in this Part as "the financial limit" ; and the regulations may in particular (in reliance on section 125(7)) specify—

(a) different levels for different descriptions of care and support;

(b) different levels for different descriptions of support.

(11) The regulations must make provision for—

(a) calculating income;

(b) calculating capital.

(12) The regulations may make provision—

(a) for treating, or not treating, amounts of a specified type as income or as capital;

(b) as to cases or circumstances in which an adult is to be treated as having, or as not having, financial resources above the financial limit.

(13) The regulations may make provision as to cases or circumstances in which a local authority is to be treated as—

(a) having carried out a financial assessment in an adult's case, and

(b) being satisfied on that basis that the adult's financial resources exceed, or that they do not exceed, the financial limit.

18 Duty to meet needs for care and support

(1) A local authority, having made a determination under section 13(1), must meet the adult's needs for care and support which meet the eligibility criteria if—

(a) the adult is ordinarily resident in the authority's area or is present in its area but of no settled residence,[and]1

(b) the adult's accrued costs do not exceed the cap on care costs, and

(c) there is no charge under section 14 for meeting the needs or, in so far as there is, condition 1, 2 or 3 is met.

(2) Condition 1 is met if the local authority is satisfied on the basis of the financial assessment it carried out that the adult's financial resources are at or below the financial limit.

(3) Condition 2 is met if—

(a) the local authority is satisfied on the basis of the financial assessment it carried out that the adult's financial resources are above the financial limit, but

(b) the adult nonetheless asks the authority to meet the adult's needs.

(4) Condition 3 is met if—

(a) the adult lacks capacity to arrange for the provision of care and support, but

(b) there is no person authorised to do so under the Mental Capacity Act 2005 or otherwise in a position to do so on the adult's behalf.

(5) A local authority, having made a determination under section 13(1), must meet the adult's needs for care and support which meet the eligibility criteria if—

(a) the adult is ordinarily resident in the authority's area or is present in its area but of no settled residence, and

(b) the adult's accrued costs exceed the cap on care costs.

(6) The reference in subsection (1) to there being no charge under section 14 for meeting an adult's needs for care and support is a reference to there being no such charge because—

(a) the authority is prohibited by regulations under section 14 from making such a charge, or

(b) the authority is entitled to make such a charge but decides not to do so.

(7) The duties under subsections (1) and (5) do not apply to such of the adult's needs as are being met by a carer.

20 Duty and power to meet a carer's needs for support

(1) A local authority, having made a determination under section 13(1), must meet a carer's needs for support which meet the eligibility criteria if—

(a) the adult needing care is ordinarily resident in the local authority's area or is present in its area but of no settled residence,

(b) in so far as meeting the carer's needs involves the provision of support to the carer, there is no charge under section 14 for meeting the needs or, in so far as there is, condition 1 or 2 is met, and

(c) in so far as meeting the carer's needs involves the provision of care and support to the adult needing care—

(i) there is no charge under section 14 for meeting the needs and the adult needing care agrees to the needs being met in that way, or

(ii) in so far as there is such a charge, condition 3 or 4 is met.

(2) Condition 1 is met if the local authority is satisfied on the basis of the financial assessment it carried out that the carer's financial resources are at or below the financial limit.

(3) Condition 2 is met if—

(a) the local authority is satisfied on the basis of the financial assessment it carried out that the carer's financial resources are above the financial limit, but

(b) the carer nonetheless asks the authority to meet the needs in question.

(4) Condition 3 is met if—

(a) the local authority is satisfied on the basis of the financial assessment it carried out that the financial resources of the adult needing care are at or below the financial limit, and

(b) the adult needing care agrees to the authority meeting the needs in question by providing care and support to him or her.

(5) Condition 4 is met if—

(a) the local authority is satisfied on the basis of the financial assessment it carried out that the financial resources of the adult needing care are above the financial limit, but

(b) the adult needing care nonetheless asks the authority to meet the needs in question by providing care and support to him or her.

(6) A local authority may meet a carer's needs for support if it is satisfied that it is not required to meet the carer's needs under this section; but, in so far as meeting the carer's needs involves the provision of care and support to the adult needing care, it may do so only if the adult needing care agrees to the needs being met in that way.

(7) A local authority may meet some or all of a carer's needs for support in a way which involves the provision of care and support to the adult needing care, even if the authority would not be required to meet the adult's needs for care and support under section 18.

(8) Where a local authority is required by this section to meet some or all of a carer's needs for support but it does not prove feasible for it to do so by providing care and support to the adult needing care, it must, so far as it is feasible to do so, identify some other way in which to do so.

(9) The reference in subsection (1)(b) to there being no charge under section 14 for meeting a carer's needs for support is a reference to there being no such charge because—

(a) the authority is prohibited by regulations under section 14 from making such a charge, or

(b) the authority is entitled to make such a charge but decides not to do so.

(10) The reference in subsection (1)(c) to there being no charge under section 14 for meeting an adult's needs for care and support is to be construed in accordance with section 18(6).

30 Cases where adult expresses preference for particular accommodation

(1) Regulations may provide that where—

(a) a local authority is going to meet needs under sections 18 to 20 by providing or arranging for the provision of accommodation of a specified type,

(b) the adult for whom the accommodation is going to be provided expresses a preference for particular accommodation of that type, and

(c) specified conditions are met,

the local authority must provide or arrange for the provision of the preferred accommodation.

(2) The regulations may provide for the adult or a person of a specified description to pay for some or all of the additional cost in specified cases or circumstances.

(3) "Additional cost" means the cost of providing or arranging for the provision of the preferred accommodation less that part of the amount specified in the personal budget for the purposes of section 26(1)(a) that relates to the provision of accommodation of that type.

24 The steps for the local authority to take

(1) Where a local authority is required to meet needs under section 18 or 20(1), or decides to do so under section 19(1) or (2) or 20(6), it must—

(a) prepare a care and support plan or a support plan for the adult concerned,

(b) tell the adult which (if any) of the needs that it is going to meet may be met by direct payments, and

(c) help the adult with deciding how to have the needs met.

(2) Where a local authority has carried out a needs or carer's assessment but is not required to meet needs under section 18 or 20(1), and does not decide to do so under section 19(1) or (2) or 20(6), it must give the adult concerned—

(a) its written reasons for not meeting the needs, and

(b) (unless it has already done so under section 13(5)) advice and information about—

(i) what can be done to meet or reduce the needs;

(ii) what can be done to prevent or delay the development by the adult concerned of needs for care and support or of needs for support in the future.

(3) Where a local authority is not going to meet an adult's needs for care and support, it must nonetheless prepare an independent personal budget for the adult (see section 28) if—

(a) the needs meet the eligibility criteria,

(b) at least some of the needs are not being met by a carer, and

(c) the adult is ordinarily resident in the authority's area or is present in its area but of no settled residence.

25 Care and support plan, support plan

(1) A care and support plan or, in the case of a carer, a support plan is a document prepared by a local authority which—

(a) specifies the needs identified by the needs assessment or carer's assessment,

(b) specifies whether, and if so to what extent, the needs meet the eligibility criteria,

(c) specifies the needs that the local authority is going to meet and how it is going to meet them,

(d) specifies to which of the matters referred to in section 9(4) the provision of care and support could be relevant or to which of the matters referred to in section 10(5) and (6) the provision of support could be relevant,

(e) includes the personal budget for the adult concerned (see section 26), and

(f) includes advice and information about—

(i) what can be done to meet or reduce the needs in question;

(ii) what can be done to prevent or delay the development of needs for care and support or of needs for support in the future.

(2) Where some or all of the needs are to be met by making direct payments, the plan must also specify—

(a) the needs which are to be so met, and

(b) the amount and frequency of the direct payments.

(3) In preparing a care and support plan, the local authority must involve—

(a) the adult for whom it is being prepared,

(b) any carer that the adult has, and

(c) any person whom the adult asks the authority to involve or, where the adult lacks capacity to ask the authority to do that, any person who appears to the authority to be interested in the adult's welfare.

(4) In preparing a support plan, the local authority must involve—

(a) the carer for whom it is being prepared,

(b) the adult needing care, if the carer asks the authority to do so, and

(c) any other person whom the carer asks the authority to involve.

(5) In performing the duty under subsection (3)(a) or (4)(a), the local authority must take all reasonable steps to reach agreement with the adult or carer for whom the plan is being prepared about how the authority should meet the needs in question.

(6) In seeking to ensure that the plan is proportionate to the needs to be met, the local authority must have regard in particular—

(a) in the case of a care and support plan, to the matters referred to in section 9(4);

(b) in the case of a support plan, to the matters referred to in section 10(5) and (6).

(7) The local authority may authorise a person (including the person for whom the plan is to be prepared) to prepare the plan jointly with the authority.

(8) The local authority may do things to facilitate the preparation of the plan in a case within subsection (7); it may, for example, provide a person authorised under that subsection with—

(a) in the case of a care and support plan, information about the adult for whom the plan is being prepared;

(b) in the case of a support plan, information about the carer and the adult needing care;

(c) in either case, whatever resources, or access to whatever facilities, the authority thinks are required to prepare the plan.

(9) The local authority must give a copy of a care and support plan to—

(a) the adult for whom it has been prepared,

(b) any carer that the adult has, if the adult asks the authority to do so, and

(c) any other person to whom the adult asks the authority to give a copy.

(10) The local authority must give a copy of a support plan to—

(a) the carer for whom it has been prepared,

(b) the adult needing care, if the carer asks the authority to do so, and

(c) any other person to whom the carer asks the authority to give a copy.

(11) A local authority may combine a care and support plan or a support plan with a plan (whether or not prepared by it and whether or not under this Part) relating to another person only if the adult for whom the care and support plan or the support plan is being prepared agrees and—

(a) where the combination would include a plan prepared for another adult, that other adult agrees;

(b) where the combination would include a plan prepared for a child (including a young carer), the consent condition is met in relation to the child.

(12) The consent condition is met in relation to a child if—

(a) the child has capacity or is competent to agree to the plans being combined and does so agree, or

(b) the child lacks capacity or is not competent so to agree but the local authority is satisfied that the combining the plans would be in the child's best interests.

(13) Regulations may specify cases or circumstances in which such of paragraphs (a) to (f) of subsection (1) and paragraphs (a) and (b) of subsection (2) as are specified do not apply.

(14) The regulations may in particular specify that the paragraphs in question do not apply as regards specified needs or matters.

27 Review of care and support plan or of support plan

(1) A local authority must—

(a) keep under review generally care and support plans, and support plans, that it has prepared, and

(b) on a reasonable request by or on behalf of the adult to whom a care and support plan relates or the carer to whom a support plan relates, review the plan.

(2) A local authority may revise a care and support plan; and in deciding whether or how to do so, it—

(a) must have regard in particular to the matters referred to in section 9(4) (and specified in the plan under section 25(1)(d)), and

(b) must involve—

(i) the adult to whom the plan relates,

(ii) any carer that the adult has, and

(iii) any person whom the adult asks the authority to involve or, where the adult lacks capacity to ask the authority to do that, any person who appears to the authority to be interested in the adult's welfare.

(3) A local authority may revise a support plan; and in deciding whether or how to do so, it—

(a) must have regard in particular to the matters referred to in section 10(5) and (6) (and specified in the plan under section 25(1)(d)), and

(b) must involve—

(i) the carer to whom the plan relates,

(ii) the adult needing care, if the carer asks the authority to do so, and

(iii) any other person whom the carer asks the authority to involve.

(4) Where a local authority is satisfied that circumstances have changed in a way that affects a care and support plan or a support plan, the authority must—

(a) to the extent it thinks appropriate, carry out a needs or carer's assessment, carry out a financial assessment and make a determination under section 13(1), and

(b) revise the care and support plan or support plan accordingly.

(5) Where, in a case within subsection (4), the local authority is proposing to change how it meets the needs in question, it must, in performing the duty under subsection (2)(b)(i) or (3)(b)(i), take all reasonable steps to reach agreement with the adult concerned about how it should meet those needs.

78 Guidance, etc.

(1) A local authority must act under the general guidance of the Secretary of State in the exercise of functions given to it by this Part or by regulations under this Part.

(2) Before issuing any guidance for the purposes of subsection (1), the Secretary of State must consult such persons as the Secretary of State considers appropriate.

(3) The Secretary of State must have regard to the general duty of local authorities under section 1(1) (promotion of individual Well-being)—

(a) in issuing guidance for the purposes of subsection (1);

(b) in making regulations under this Part.

Care Support (Eligibility) Criteria Regulations 2015

Reg 2 Needs which meet the eligibility criteria: adults who need care and support

(1) An adult's needs meet the eligibility criteria if—

(a) the adult's needs arise from or are related to a physical or mental impairment or illness;

(b) as a result of the adult's needs the adult is unable to achieve two or more of the outcomes specified in paragraph (2); and

(c) as a consequence there is, or is likely to be, a significant impact on the adult's well-being.

(2) The specified outcomes are—

(a) managing and maintaining nutrition;

(b) maintaining personal hygiene;

(c) managing toilet needs;

(d) being appropriately clothed;

(e) being able to make use of the adult's home safely;

(f) maintaining a habitable home environment;

(g) developing and maintaining family or other personal relationships;

(h) accessing and engaging in work, training, education or volunteering;

(i) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and

(j) carrying out any caring responsibilities the adult has for a child.

(3) For the purposes of this regulation an adult is to be regarded as being unable to achieve an outcome if the adult—

(a) is unable to achieve it without assistance;

(b) is able to achieve it without assistance but doing so causes the adult significant pain, distress or anxiety;

(c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or

(d) is able to achieve it without assistance but takes significantly longer than would normally be expected.

(4) Where the level of an adult's needs fluctuates, in determining whether the adult's needs meet the eligibility criteria, the local authority must take into account the adult's circumstances over such period as it considers necessary to establish accurately the adult's level of need.

Reg 3 Needs which meet the eligibility criteria: carers

(1) A carer's needs meet the eligibility criteria if—

(a) the needs arise as a consequence of providing necessary care for an adult;

(b) the effect of the carer's needs is that any of the circumstances specified in paragraph (2) apply to the carer; and

(c) as a consequence of that fact there is, or is likely to be, a significant impact on the carer's well-being.

(2) The circumstances specified in this paragraph are as follows—

(a) the carer's physical or mental health is, or is at risk of, deteriorating;

(b) the carer is unable to achieve any of the following outcomes—

(i) carrying out any caring responsibilities the carer has for a child;

(ii) providing care to other persons for whom the carer provides care;

(iii) maintaining a habitable home environment in the carer's home (whether or not this is also the home of the adult needing care);

(iv) managing and maintaining nutrition;

(v) developing and maintaining family or other personal relationships;

(vi) engaging in work, training, education or volunteering;

(vii) making use of necessary facilities or services in the local community, including recreational facilities or services; and

(viii) engaging in recreational activities.

(3) For the purposes of paragraph (2) a carer is to be regarded as being unable to achieve an outcome if the carer—

(a) is unable to achieve it without assistance;

(b) is able to achieve it without assistance but doing so causes the carer significant pain, distress or anxiety; or

(c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the carer, or of others.

(4) Where the level of a carer's needs fluctuates, in determining whether the carer's needs meet the eligibility criteria, the local authority must take into account the carer's circumstances over such period as it considers necessary to establish accurately the carer's level of need.

Extracts of the Care Act Statutory Guidance

Assessment

6.1 The assessment and eligibility process is one of the most important elements of the care and support system. The assessment is one of the key interactions between a local authority and an individual, whether an adult needing care or a carer. The process must be person-centred throughout, involving the person and supporting them to have choice and control.

6.2 The assessment process starts from when local authorities begin to collect information about the person, and will be an integral part of the person's journey through the care and support system as their needs change. It should not just be seen as a gateway to care and support, but should be a critical intervention in its own right, which can help people to understand their situation and the needs they have, to reduce or delay the onset of greater needs, and to access support when they require it. It can also help people to understand their strengths and capabilities, and the support available to them in the community and through other networks and services.

6.3 An 'assessment' must always be appropriate and proportionate. It may come in different formats and can be carried out in various ways, including but not limited to:

- a face-to-face assessment between the person and an assessor, whose professional role and qualifications may vary depending on the circumstances, but who must always be appropriately trained and have the right skills and knowledge
- a supported self-assessment, which should use similar assessment materials as used in other forms of needs or carers' assessments, but where the person completes the assessment themselves and the local authority assures itself that it is an accurate reflection of the person's needs (for example, by consulting with other relevant professionals and people who know the person with their consent)
- an online or phone assessment, which can be a proportionate way of carrying out assessments (for example where the person's needs are less complex or where the person is already known to the local authority and it is carrying out an assessment following a change in their needs or circumstances)

- a joint assessment, where relevant agencies work together to avoid the person undergoing multiple assessments (including assessments in a prison, where local authorities may need to put particular emphasis on cross-agency cooperation and sharing of expertise)
- a combined assessment, where an adult's assessment is combined with a carer's assessment and/or an assessment relating to a child so that interrelated needs are properly captured and the process is as efficient as possible

6.4 People may approach a local authority for an assessment, or be referred by a third party, for a number of reasons. The 'assessment' which they receive must follow the core statutory obligations, but the process is flexible and can be adapted to best fit with the person's needs, wishes and goals. The nature of the assessment will not always be the same for all people, and depending on the circumstances, it could range from an initial contact or triage process which helps a person with lower needs to access support in their local community, to a more intensive, ongoing process which requires the input of a number of professionals over a longer period of time.

6.15 During the assessment, local authorities must consider all of the adult's care and support needs, regardless of any support being provided by a carer. Where the adult has a carer, information on the care that they are providing can be captured during assessment, but it must not influence the eligibility determination. After the eligibility determination has been reached, if the needs are eligible or the local authority otherwise intends to meet them, the care which a carer is providing can be taken into account during the care and support planning stage. The local authority is not required to meet any needs which are being met by a carer who is willing and able to do so, but it should record where that is the case. This ensures that the entirety of the adult's needs are identified and the local authority can respond appropriately if the carer feels unable or unwilling to carry out some or all of the caring they were previously providing.

6.18 Carers' assessments must seek to establish not only the carer's needs for support, but also the sustainability of the caring role itself, which includes both the practical and emotional support the carer provides to the adult. Therefore, where the local authority is carrying out a carer's assessment, it must include in its assessment a consideration of the carer's potential future needs for support. Factored into this must be a consideration of whether the carer is, and will continue to be, able and willing to care for the adult needing care. Some carers may need support in recognising issues around sustainability, and in recognising their own needs. This will allow local authorities to make a realistic evaluation of the carer's present and future needs for support and whether the caring relationship is sustainable. Where appropriate these views should be sought in a separate conversation independent from the adult's needs assessment.

6.29 An assessment should be carried out over an appropriate and reasonable timescale taking into account the urgency of needs and a consideration of any fluctuation in those needs. Local authorities should inform the individual of an indicative timescale over which their assessment will be conducted and keep the person informed throughout the assessment process.

...

8.50 Local authorities are not required to charge a carer for support and indeed in many cases it would be a false economy to do so. When deciding whether to charge, and in determining what an appropriate charge is, a local authority should consider how it wishes to express the way it values carers within its local community as partners in care, and recognise the significant contribution carers make. Carers help to maintain the health and wellbeing of the person they care for, support this person's independence and enable them to stay in their own homes for longer. In many cases of course, carers voluntarily meet eligible needs that the local authority would otherwise be required to meet. Local authorities should consider carefully the likely impact of any charges on carers, particularly in terms of their willingness and ability to continue their caring responsibilities. It may be that there are circumstances where a nominal charge may be appropriate, for example to provide for a service which is subsidised but for which the carer may still pay a small charge, such as a gym class. Ultimately, a local authority should ensure that any charges do not negatively impact on a carer's ability to look after their own health and wellbeing and to care effectively and safely.

8.51 While charging carers may be appropriate in some circumstances, it is very unlikely to be efficient to systematically charge carers for meeting their eligible needs. This is because excessive charges are likely to lead to carers refusing support, which in turn will lead to carer breakdown and local authorities having to meet more eligible needs of people currently cared for voluntarily. As an example, work carried out by Surrey County Council found that if even 10% of people with care and support needs in families supported by carers presented to the council with eligible needs as a result of carer breakdown, the resulting cost would be 3 times the current total budget for carer support. The ADASS produced the Economic Case for Investment in Carers, a short factsheet for local authorities to use in considering whether to put in place a policy of charging carers, setting out the evidence that charging would be a false economy.

What does it mean to 'meet needs'?

10.10 'Meeting needs' is an important concept under the Act and moves away from the previous terminology of 'providing services'. This enables a greater variety of approaches in how needs can be met, developed through care and support planning as described in this chapter. The concept of 'meeting needs' is intended to be broader than a duty to provide or arrange a particular service. Because a person's needs are specific to them, there are many ways in which their needs can be met. The intention behind the legislation is to encourage this diversity, rather than point to a service or solution that may be neither what is best nor what the person wants. The purpose of the care and support planning process is to agree how a person's needs should be met, and therefore how the local authority will discharge its duty, or its power, to do so.

10.11 There are a number of broad options for how needs could be met, and the use of one or more of these will depend on the circumstances. Section 8(2) of the Act gives some examples of ways of meeting needs, and would cover:

- the local authority directly providing some type of support, for example by providing a reablement or short-term respite service
- making a direct payment, which allows the person to purchase their own care and support
- some combination of the above, for example the local authority arranging a homecare service whilst also providing a direct payment to meet other needs

10.12 Where the local authority provides or arranges for care and support, the type of support may itself take many forms. These may include more traditional 'service' options, such as care homes or homecare, but may also include other types of support such as assistive technology in the home or equipment/adaptations, and approaches to meeting needs should be inclusive of less intensive or service-focused options.

10.13 Needs may be met through types of care and support which are available universally, including those which are not directly provided by the local authority. For example, in some cases needs could be met by a service which is also made available as part of a local authority's plans for preventing or reducing needs for care and support (under Section 2 of the Act). Needs could also be met, for example, by putting a person in contact with a local community group or voluntary sector organisation.

10.14 The examples of how needs can be met listed in the Act are not exhaustive, but cover the most common means of meeting needs. In addition, there are other methods which may be suitable for meeting a person's needs, for example by arranging an individual service fund (see chapter 11 on personal budgets which also includes detail on individual service funds). This is a budget held by a provider, rather than by the local authority or the individual. The local authority makes a payment to the provider, which then holds a budget over which the individual has control.

Timeliness and regularity of reviews

13.31 In the absence of any request of a review, or any indication that circumstances may have changed, the local authority should conduct a periodic review of plan. As stated earlier, this could be indicated at the planning stage by including an anticipated review date to allow for future planning. In addition, local authorities may wish to align the periodic review of the plan, with the compulsory review of the direct payment arrangements, where this is appropriate.

13.32 It is the expectation that authorities should conduct a review of the plan no later than every 12 months, although a light-touch review should be considered 6–8 weeks after agreement and sign-off of the plan and personal budget, to ensure that the arrangements are accurate and there are no initial issues to be aware of. This light-touch review should also be considered after revision of an existing plan to ensure that the new plan is working as intended, and in cases where a person chooses a direct payment, should be aligned with the review of the making of the direct payment (see chapter 12 on direct payments).

13.33 The periodic review should be proportionate to the needs to be met, and the process should not contain any surprises for the person concerned. Periodic reviews and reviews in general must not be used to arbitrarily reduce a care and support package. Such behaviour would be unlawful under the Act as the personal budget must always be an amount appropriate to meet the person's needs. Any reduction to a personal budget should be the result of a change in need or circumstance.

13.34 The review should be performed as quickly as is reasonably practicable. As with care and support planning, it is expected that in most cases the revision of the plan should be completed in a timely manner proportionate to the needs to be met. Where there is an urgent need to intervene, local authorities should consider implementing interim packages to urgently meet needs while the plan is revised. However, local authorities should work with the person to avoid such circumstances wherever possible by ensuring that any potential emergency needs are identified as part of the care and support planning stage and planned for accordingly.

Guidance: [Withdrawn] Responding to COVID-19: the ethical framework for adult social care

Updated 28 April 2021. This guidance was withdrawn on 1 April 2022. The information in this guidance has been superseded by: Infection prevention and control in adult social care: COVID-19 supplement.

https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care

Introduction

The current novel coronavirus (COVID-19) outbreak, which began in December 2019, will have major implications for health and care services in the UK.

As set out in the coronavirus action plan, published on 3 March 2020, the UK's health and social care systems have planned extensively over the years for a pandemic and are well prepared to offer substantial protection to the public. Of course, the exact response to COVID-19 will be tailored to the nature, scale and location of the threat as our understanding of this develops.

Local authorities and the wider health and care workforce are faced with difficult decisions every day. However, planning for and responding to COVID-19 as it develops will undoubtedly require making difficult decisions under new and exceptional pressures with limited time, resources or information.

These decisions could be personal, relating to our families, carers and communities, or have wider impacts on the organisation and delivery of our health and care services. Decisions will need to be made in accordance with the law and official guidance issued and applicable at the time, and while meeting statutory duties and professional responsibilities.

This framework intends to provide support to ongoing response planning and decision-making to ensure that ample consideration is given to a series of ethical values and principles when organising and delivering social care for adults.

Recognising increasing pressures and expected demand, it might become necessary to make challenging decisions on how to redirect resources where they are most needed and to prioritise individual care needs. This framework intends to serve as a guide for these types of decisions and reinforce that consideration of any potential harm that might be suffered, and the needs of all individuals, are always central to decision-making.

Equal concern and respect should be given to all individuals, their families and carers, and communities, as well as the professionals and volunteers that we will be relying on to ensure the delivery of our services and ambitions.

As the outbreak affects society as a whole, everyone will have their role to play to support the ongoing and future response. It is vital that professionals, organisations and public agencies work together at local and national level, and that planning and response activities at national, regional and local level are well-coordinated. Appropriate records must be kept of which decisions are taken and their justifications to both ensure accountability and to share learning with others during and as the outbreak develops.

This document has been adapted and refreshed from the ethical framework first developed by the Committee on Ethical Aspects of Pandemic Influenza in 2007, which was later revised by the Department of Health and Social Care (DHSC) in 2017.

How to use the framework

This framework is aimed at planners and strategic policy makers at local, regional and national level to support response planning and organisation of adult social care during and as COVID-19 develops. It also aims to support the work of professionals and others in the health and social care workforce who are developing policies and responding to the outbreak, in line with their own professional codes of conduct and regulations.

These principles can also be applied more widely in the social care sector.

Social care is a locally led and delivered service built on a detailed understanding of individuals and their families, communities and cultures. Social workers, occupational therapists and nurses form the core professional group and have clear responsibilities and accountabilities to their own professional codes and guidelines.

Local professional leaders, such as principal social workers and principal occupational therapists, will be key in ensuring this framework is applied and understood. As such, the skills of these professionals should be used to help develop and review locally agreed processes.

Alongside ethical considerations, every decision will require consideration of individual wellbeing, overall public good and the resources that are available. The values and principles should serve as a starting point to guide decision-making, supported by the views of lead professionals, collaboration across disciplines and organisations, and the extent of information available in each particular circumstance.

The ethical values and principles are equally relevant to those in need of social care who may face increased

vulnerability, those who may become in need of social care, and the health and social care workforce who may face new and unexpected burdens when making difficult decisions and providing care and support during and as COVID-19 develops.

It might be useful to use the framework as a checklist to ensure ethical considerations are taken in to account, however, the values and principles described in this document are not exhaustive. When implementing the ethical values and principles in urgent and uncertain circumstances, you may encounter tension between them which will require a judgement to be made on the extent that a particular value or principle can be applied in the context of each particular decision.

In all instances, respect and reasonableness should be used as the fundamental, underpinning principles which guide planning and support judgements.

The values and principles

This section outlines each ethical value and principle and associated actions and best practice when considering and applying them. These should be considered alongside professional codes of conduct and the most recent official guidance and legislation where these apply.

The principles are numbered for ease of reference but are not ranked in order of significance or exhaustive. There are no absolute answers to making the correct or most ethical decisions.

Where resources are constrained and there are surges in demand, it may not be feasible to consider all the principles or the actions below them. Each principle must be considered to the extent possible in the context of each circumstance with appropriate risk management and considerations of individual wellbeing, overall public good and available information and resources.

1. Respect

This principle is defined as recognising that every person and their human rights, personal choices, safety and dignity matters.

To ensure people are treated with respect, those making decisions should:

- provide people with the opportunity to express their views on matters that affect their care, support and treatment
- respect people's personal choices as much as possible, while considering and communicating implications for the present and future
- keep people as informed as possible of what is happening or what is expected to happen in any given circumstance
- where a person may lack capacity (as defined in the Mental Capacity Act), ensure that a person's best interests and support needs are considered by those who are responsible or have relevant legal authority to decide on their behalf
- strive to support people to get what they are entitled to, subject to available resources, ensuring that there is a fair judgement and clear justification for any decisions made on prioritisation

2. Reasonableness

This principle is defined as ensuring that decisions are rational, fair, practical, and grounded in appropriate processes, available evidence and a clear justification.

When considering how reasonable a decision is, those making decisions should:

- ensure the decision made is practical with a reasonable chance of working
- base decisions on the evidence and information that is available at the time, being conscious of known risks and benefits that might be experienced
- consider alternative options and ways of thinking, being conscious of diverse views from cultures and communities
- use a clear, fair decision-making process which is appropriate for the time and context a decision must be made in, and allows for contributions to be considered seriously

This principle should be considered alongside relevant equalities-related legal and policy frameworks. Although resources may become stretched, it should be upheld that people with comparable needs should have the same opportunity to have those needs met.

3. Minimising harm

This principle is defined as striving to reduce the amount of physical, psychological, social and economic harm that the outbreak might cause to individuals and communities. In turn, this involves ensuring that individual organisations and society as a whole cope with and recover from it to their best ability.

It's important that those responsible strive to:

- acknowledge and communicate that everyone has a role to play in minimising spread, for example by practising thorough hand-washing or social distancing
- minimise the risk of complications in the event that someone is unwell
- provide regular and accurate updates within communities and organisations
- share learning from local, national and global experiences about the best way to treat and respond to the outbreak as understanding of COVID-19 develops
- enable care workers and volunteers to make informed decisions which support vulnerable people

4. Inclusiveness

This principle is defined as ensuring that people are given a fair opportunity to understand situations, be included in decisions that affect them, and offer their views and challenge. In turn, decisions and actions should aim to minimise inequalities as much as possible.

To ensure inclusiveness to the extent possible, those making decisions should:

- involve people in aspects of planning that affect them, their care and treatment, and their communities
- involve families and carers in aspects of planning that affect them and the individual who they care for
- ensure that no particular person or group is excluded from becoming involved
- consider any disproportionate impacts of a decision on particular people or groups
- provide appropriate communications to all involved, using the range of communication methods and formats needed to reach different people and communities
- be transparent and have a clear justification when it is decided to treat a person or group in a different manner than others, that which shows why it is fair to do so

Where appropriate, the above should be considered alongside relevant equalities-related legal and policy frameworks that will inform inclusive decision-making by ensuring that specific barriers to service use are minimised for those who may be or become disadvantaged as the outbreak develops.

5. Accountability

This principle is defined as holding people, and ourselves, to account for how and which decisions are made. In turn, this requires being transparent about why decisions are made and who is responsible for making and communicating them.

Those responsible must be accountable for their decisions and actions by:

- acting on and delivering the outcomes required by their responsibilities and duties to individuals, their families and carers, and staff
- adhering to official guidance, statutory duties, and professional regulations at the time
- being transparent about how and which decisions need to be made and on what basis
- being prepared to justify which decisions are made and why, ensuring that appropriate records are being kept
- supporting others to take responsibility for their decisions and actions

Within organisations, this will also entail:

- continuing to carry out professional roles and responsibilities unless it is deemed reasonable not to do so
- providing an environment in which staff can work safely, effectively and collaboratively, which protects their health and wellbeing as the outbreak develops
- providing appropriate guidance and support to staff who may be asked to work outside of their normal area of expertise or be unable to carry out some of their daily activities
- having locally-agreed processes in place to handle ethical challenges during and in the aftermath of the outbreak

6. Flexibility

This principle is defined as being responsive, able, and willing to adapt when faced with changed or new circumstances. It is vital that this principle is applied to the health and care workforce and wider sector, to facilitate agile and collaborative working.

To ensure flexibility, those making decisions should be prepared to:

- respond and adapt to changes as and when they occur, for example in the event of new information arising or changed levels of demand
- ensure that plans and policy have room for flexibility and innovation where necessary
- provide people with as much opportunity as possible to challenge decisions that affect them in the time that is available
- ensure that the health and care workforce is supported to work collaboratively across disciplines and organisations, as agile and resilient as possible
- review organisational practices, standard approaches and contractual arrangements that may obstruct these ambitions

7. Proportionality

This principle is defined as providing support that is proportional to needs and abilities of people, communities and staff, and the benefits and risks that are identified through decision-making processes.

When considering proportionality, those responsible should:

- assist people with care and support needs to the extent possible
- act on statutory or special responsibilities, while noting any duties that might be amended as the outbreak develops
- provide support for those who have extra or new responsibilities to care for others
- provide support for those who are asked to take increased risks or face increased burdens, while attempting to minimise these as far as possible
- provide appropriate support and communications to staff who may experience unexpected or new pressures

8. Community

This principle is defined as a commitment to get through the outbreak together by supporting one another and strengthening our communities to the best of our ability.

Everyone involved will have a role to play in the response to the outbreak and will be affected in one way or another, and therefore should:

- work with and support one another to plan for, respond to, and cope with the outbreak
- support our networks and communities to strengthen their response and meet needs that arise, for example by helping and caring for neighbours, friends and family
- be conscious of own behaviour and decisions, and how this may impact on others
- share learning from own experiences that may help others

Guidance: [Withdrawn] Care Act easements: guidance for local authorities

Updated 29 June 202. This guidance was withdrawn on 22 July 2021

The Care Act easements provision in the Coronavirus Act 2020 expired on 29 June 2021 and is no longer in force.

Applies to: England

1. Introduction

This guidance sets out how local authorities can use the new Care Act easements, created under the Coronavirus Act 2020, to ensure the best possible care for people in our society during this exceptional period.

2. Purpose of the easements

Local authorities and care providers are already facing rapidly growing pressures as more people need support because unpaid carers are unwell or unable to reach them, and as care workers are having to self-isolate or are unable to work for other reasons.

The government has put in place a range of measures to help the care system manage these pressures. Local authorities should do everything they can to continue meeting their existing duties prior to the Coronavirus Act provisions coming into force. In the event that they are unable to do so, it is essential that they are able to streamline present assessment arrangements and prioritise care so that the most urgent and acute needs are met.

The powers in the Act enable them to prioritise more effectively where necessary than would be possible under the Care Act 2014 prior to its amendment (referred to in this guidance as the Care Act). They are time-limited and are there to be used as narrowly as possible.

3. What the powers actually change

The changes fall into 4 key categories, each applicable for the period the powers are in force:

1. Local authorities will not have to carry out detailed assessments of people's care and support needs in compliance with pre-amendment Care Act requirements. However, they will still be expected to respond as soon as possible (within a timeframe that would not jeopardise an individual's human rights) to requests for care and support, consider the needs and wishes of people needing care and their family and carers, and make an assessment of what care needs to be provided. Annex B of the guidance provides more information.
2. Local authorities will not have to carry out financial assessments in compliance with pre-amendment Care Act requirements. They will, however, have powers to charge people retrospectively for the care and support they receive during this period, subject to giving reasonable information in advance about this, and a later financial assessment. This will ensure fairness between people already receiving care and support before this period, and people entering the care and support system during this period. Annex B of the guidance provides more information.
3. Local authorities will not have to prepare or review care and support plans in line with the pre-amendment Care Act provisions. They will however still be expected to carry out proportionate, person-centred care planning which provides sufficient information to all concerned, particularly those providing care and support, often at short notice. Where they choose to revise plans, they must also continue to involve users and carers in any such revision. Annex B of the guidance provides more information.
4. The duties on local authorities to meet eligible care and support needs, or the support needs of a carer, are replaced with a power to meet needs. Local authorities will still be expected to take all reasonable steps to continue to meet needs as now. In the event that they are unable to do so, the powers will enable them to prioritise the most pressing needs, for example enhanced support for people who are ill or self-isolating, and to temporarily delay or reduce other care provision. Annex C provides further guidance about the principles and approaches which should underpin this.

4. Protections and safeguards

The overriding purpose of these easements is to ensure the best possible provision of care to people in these exceptional circumstances. In order to help ensure that they are applied in the best possible way, with the greatest regard towards the needs and wishes of care users and their carers, the following protections and safeguards will apply.

The easements took legal effect on 31 March 2020, but should only be exercised by local authorities where this is essential in order to maintain the highest possible level of services. They should comply with the pre-amendment Care Act provisions and related Care and Support Statutory Guidance for as long and as far as possible.

They are temporary. The Secretary of State will keep them under review and terminate them, on expert clinical and social care advice, as soon as possible.

All assessments and reviews that are delayed or not completed will be followed up and completed in full once the easements are terminated.

Local authorities will remain under a duty to meet needs where failure to do so would breach an individual's human rights under the European Convention on Human Rights (ECHR). These include, for example, the right to life under Article 2 of the ECHR, the right to freedom from inhuman and degrading treatment under Article 3 and the right to private and family life under Article 8.

The Care Quality Commission (CQC) will continue to provide oversight of providers under existing legislation. Throughout this period the CQC will take a pragmatic approach to inspection and proportionate action as necessary while maintaining its overriding purpose of keeping people safe.

Other important duties on local authorities remain in place:

- Duties in the Care Act to promote wellbeing and duties relating to safeguarding adults at risk remain in place. Further guidance on safeguarding during this period is at annex D
- Duties in the Mental Capacity Act 2005 relating to Deprivation of Liberty Safeguards (DoLS) remain in place. Guidance on the operation of DoLS during this period has been published separately
- Local authorities' duties relating to prevention and providing information and advice also remain in place. The provision of information and advice for public reassurance will be particularly important during this period. To aid good communications, local authorities should continue to draw on their helpful relationships with trusted partners in the voluntary sector as well as on a full range of digital and other channels which help reach people with differing needs and in different circumstances during this period (for example, to make up for any closure or reduced service of libraries)
- Duties imposed under the Equality Act 2010 also remain, including duties to make reasonable adjustments, the Public Sector Equality Duty and duties towards people with protected characteristics. These should underpin any decisions made with regard to the care and support someone receives during this period

5. Principles to govern use of the powers

The Care Act embodies a principled, person-centred and values-based approach to all aspects of the provision of social care. It is essential that these principles and values are maintained during this period.

Local authorities will be expected to observe the ethical framework for adult social care. This provides a structure for local authorities to measure their decisions against, and reinforces that the needs and wellbeing of individuals should be central to decision-making. In particular it should underpin challenging decisions about the prioritisation of resources where they are most needed.

Alongside the framework, local authorities should continue to respect the principles of personalisation and co-production. These are embodied in the following statement produced with the support of Think Local, Act Personal (TLAP):

I am supported to make decisions by people who see things from my point of view, with concern for what matters to me, my wellbeing and health. (Making it Real)

We find ourselves in unprecedented times with citizens facing significant uncertainty. This is especially true for those of us who receive social care support and who care for people with support needs. However, the fundamental principles of personalisation and co-production underpinning the Care Act should not be removed as a result of emergency guidance and key statements set out in the Making it Real framework ought to be viewed as immovable.

Working together matters now more now than ever. Genuine co-production will ensure the best possible decision-making and the best possible outcomes for both citizens and the workforce. This is critical if we are to save time and prevent costly mistakes. This will require the local authority to respond flexibly in spite of pressure to respond – at pace and scale – to increasing demand.

We expect and trust that local authorities will adhere to the principle of co-production and continue to view those of us in receipt of support, or carers providing support, as equal partners. We continue to be experts in our own care and support whatever the circumstances.

Now is the time to reinforce co-production, not dispense with it.

6. Steps local authorities should take before exercising the Care Act easements

A local authority should only take a decision to begin exercising the Care Act easements when the workforce is significantly depleted, or demand on social care increased, to an extent that it is no longer reasonably practicable for it to comply with its Care Act duties (as they stand prior to amendment by the Coronavirus Act) and where to continue to try to do so is likely to result in urgent or acute needs not being met, potentially risking life. Any change resulting from such a decision should be proportionate to the circumstances in a particular local authority.

Social care varies greatly across local authorities and the decision to operate the easements should be taken locally. It should be agreed by the director of adult social services in conjunction with or on the recommendation of the principal social worker (PSW). The director of adult social services and the PSW must ensure that their lead member has been involved and briefed as part of this decision-making process. The Health and Wellbeing Board should be kept informed. The decision should also be fully informed by discussion with the local NHS clinical commissioning group leadership.

Local authorities should have a record of the decision with evidence that was taken into account. Where possible the record should include the following:

- the nature of the changes to demand or the workforce
- the steps that have been taken to mitigate against the need for this to happen
- the expected impact of the measures taken
- how the changes will help to avoid breaches of people's human rights at a population level
- the individuals involved in the decision-making process
- the points at which this decision will be reviewed again

This decision should be communicated to all providers, service users, carers and local MPs. The accessibility of communication to service users and carers should be considered.

Local authorities should notify the Department of Health and Social Care (DHSC) using the Care Act Easements Notification Form when:

- they decide to start streamlining assessments and/or prioritising services under these easements
- the use of easements changes
- they resume full Care Act duties

This form should be completed and sent on each occasion to CareActEasements@dhsc.gov.uk.

Information received will be held and shared with CQC, the Association of Directors of Adult Social Services (ADASS), the Local Government Association (LGA) and other relevant parties. Details of which local authorities are operating under easements will be publicly available for transparency.

7. Interaction with other changes

This guidance is to be read alongside the hospital discharge service: policy and operating model. This makes clear that local authorities should make provision for Care Act assessments of need, financial assessments and longer-term care planning if necessary.

From 1 September 2020, new or extended health and care support will be funded for a period of up to 6 weeks, for people being discharged from hospital, or to provide urgent care for those who would otherwise have been admitted to hospital.

Provisions in the Coronavirus Act 2020 allowed NHS bodies to postpone NHS continuing healthcare (CHC) assessments until the end of the emergency period. CHC assessments will resume from 1 September 2020. Guidance has been published on restarting CHC processes.

8. Oversight

DHSC will keep the content of this guidance and adherence to it under regular review, in discussion with local authorities, care providers, user and carer representative bodies, and the CQC.

This guidance and the ethical framework for adult social care fall under schedule 12 of the Coronavirus Act 2020. Schedule 12 to that Act gives the Secretary of State a power to direct local authorities to comply with this guidance and the ethical framework, and DHSC will keep this under review.

Annex A: local decision-making relating to the easements

This annex sets out recommended governance and decision-making for directors of adult social services and PSWs in relation to use of the Care Act easements.

Introduction

During this period local authorities may need to take difficult decisions that impact on the way they respond to their responsibilities for care and support and their statutory functions. There should therefore be clear professional oversight and, where relevant, professional sign-off for such decisions as well as evidence that due consideration has been given to the possible consequences.

The Coronavirus Act does not give authority to block, restrict or withdraw whole services. It enables local authorities to make and apply person-centred decisions about who is most in need of care, and who might need to have care and support temporarily reduced or withdrawn in order to make sure those with highest need are prioritised.

Such decisions will in some cases be challenging, and therefore should always be made within the remit of the DHSC ethical framework. Importantly, they should be taken only where demand pressures and availability of staff in the coming period mean that the full range of services under the Care Act can no longer be delivered. This should be differentiated from decisions that need to be made in response to the government's guidance about social distancing. For example, it may be decided to close a service because it is no longer safe to keep people together in a building. However, this does not mean those people do not need the equivalent level of support at this time. In this example, staff might be asked to provide the equivalent level of support. The equivalent service might be an alternative, but it is to reduce the risk of breaching the social distancing guidance.

Assessments, reviews and changes to care packages

The Care Act pre-amendment currently allows local authorities to prioritise and review in differing ways. Local authorities should continue to be as flexible as possible, and ensure they stay within government guidelines around social distancing and self-isolating.

Decisions about assessments or reviews, and decisions to either reduce or alter care packages will have an impact on the people being supported as well as their carers. Such decisions must also take account of risks both current and potential should the situation change for the person and/or their carers.

Where people decide to cancel or suspend their own care and support and manage alone or with support of their own family and community networks, this will mostly be for the person to decide themselves. However, where there are concerns that this may lead to unmanageable risk or safeguarding issues, practice oversight should be applied. This is not to undermine the views of the individual making the decisions about their care, but to ensure that, where necessary, the local authority in conjunction with the individual and their family have considered the possible consequences and the principles of safeguarding have been upheld.

Deciding to apply the easements

It is important that any decisions made in relation to Care Act easements are informed by discussions with local partners, in particular local senior NHS leadership. Health and wellbeing boards should also be informed about a decision to start operating under the easements.

Recording by local authorities remains a priority and will them to ensure accountability and provide evidence for the thought processes behind the decisions they will be making.

The following table sets out decision-making processes for local authorities. These decisions are not necessarily sequential but should follow a situation where there are increasing pressures on adult social care delivery. Key stages can be enacted together or separately over time so long as the decision to do so is evidenced and follows the guidance set out below.

Decision-making tables

Operating under the pre-amendment Care Act

Stage	Decision	Process
Stage 1: Operating under the pre-amendment Care Act	Business as usual	To continue at this stage for as long as is feasible
Stage 2: Applying flexibilities under the pre-amendment Care Act	Decision for Individual service type to prioritise short-term allocation of care and support using current flexibilities within the Care Act	Where COVID-19-related absence means service types need to be changed, delayed or cancelled short term within that service type, for example home care or supported living, the relevant senior manager / assistant director should consult the PSW and should detail the: reason the decision needs to be taken; impact of the decision on the people who ordinarily use the service; impact of the decision on families and carers of people who ordinarily use the service; and possible alternative sources of care and support and the likelihood of this being available. Where the PSW is satisfied, this position can then be presented to the director of adult social services (or alternate locally agreed senior) for a final decision about moving into stage 2 It is important to note that all other services may well continue to deliver their services as business as usual

Operating under the Care Act easements

Stage	Decision	Process
Stage 3: Streamlining services under Care Act easements	Decision to operate under Care Act easements as laid out by the Coronavirus Act	The Care Act easements allow local authorities to cease formal Care Act assessments, applications of eligibility and reviews. However, there is an expectation in the Act that local authorities will do everything they can to continue to meet need as was originally set out in the Care Act. Where the impact of the pandemic is making this unachievable or untenable, local authorities will need to make the decision to cease carrying out those eased Care Act functions and move to a position of proportionate assessment and planning. The relevant assistant director / senior manager will need to consult the PSW and be clear about the: reason the decision needs to be taken; impact of the decision on the people who ordinarily use the service; and impact of the decision on families and carers of people who ordinarily use the service. If the PSW is satisfied that the Care Act easements need to be enacted, a meeting of the senior management board should be called for a final decision. The decision should also consider and be informed by a conversation with the local NHS leadership. The director of adult social services and the PSW should ensure that their lead member has been involved and briefed as part of this decision-making process. DHSC should be notified using the Care Act easements notification form.

Stage	Decision	Process
Stage 4: Prioritisation under Care Act easements	Whole system prioritising care and support	Where local authorities need to make decisions about changing support for people, they should consider and allocate capacity across the whole of adult social care. This may mean allocating resource from some service types that may not be under pressure to support those that are. An example might be where a local authority is faced with a decision about reducing personal care for one person so that another gets the help they need to eat. In this situation, the relevant assistant director / senior manager should consult the PSW. They should detail the: reason the decision needs to be taken; impact of the decision on the people who ordinarily use the service; impact of the decision on families and carers of people who ordinarily use the service; possible alternative sources of care and support and the likelihood of this being available. If a local authority decides it may need to move into stage 4, the PSW should call an emergency decision meeting of the director of adult social services where a decision about whether and how to prioritise care across adult social care (ASC) will need to be made. Sufficient care and support will have to remain in place at all times in order to ensure that the Convention rights of all those in need of care and support, and of carers, are respected. The director of adult social services and the PSW must ensure that their lead member has been involved and briefed as part of this decision-making process. DHSC should be notified using the Care Act easements notification form. Any decisions taken to prioritise or reduce support should be reviewed every 2 weeks with the PSW. Full service should be restored as soon as is reasonably possible.

Business continuity planning

Where provider services have submitted business continuity plans that have implications for direct services for people with care and support needs, professional practice as well as business oversight will be needed. Accountability for all such decisions lies with the local authority and provider services should not be making decisions about restricting or removing care. Any such decisions should be made in accordance with the process laid out in the prioritisation decision-making table above.

Annex B: Guidance on streamlining assessments and reviews

Needs and carer assessment

During this period, local authorities will still be expected to consider people's needs and the easements will only apply when it is no longer possible for them to carry out their pre-amendment Care Act duties in full.

The points in this section apply equally to people likely to be in need of care and support and carers likely to be in need of support.

Local authorities will remain under a duty to meet needs where failure to do so would breach an individual's human rights under the ECHR. These include, for example, the right to life under Article 2 of the ECHR, the right to freedom from inhuman and degrading treatment under Article 3 and the right to private and family life under Article 8.

However, to ensure that local authorities are able to respond to increased pressures on the social care sector due to COVID-19, for the duration of the Coronavirus Act's provisions, local authorities may have to reduce the extent to which they would ordinarily do a needs or carers assessment, check that people's needs are eligible, or conduct a financial assessment.

Local authorities should still assess people's social care and support needs throughout this period and should make a written record of this assessment. PSWs should ensure that proportionate professional recording is maintained and may consider a single alternate document for local use.

It is crucial that local authorities are able to evidence their decision, demonstrate their professional judgement, apply the ethical framework for adult social care and, where necessary, record that they have considered the Convention Rights.

The easements also relieve local authorities of the duty to undertake assessments of children transitioning to adult social care under sections 58 and 59 of the Care Act.

It may not be possible or necessary for assessments themselves to be face to face. Local authorities should therefore consider whether assessments could be delivered through other means, taking into consideration people's cognitive and communication needs and mental capacity, including:

- use of a third party/allied professional to carry out needs assessments as trusted assessors. It would also be appropriate for adults in need of care and support, or carers who are being assessed, to ask the local authority to liaise with other persons or professionals to help complete the check. Paragraph 6.99 in the care and support statutory guidance provides more information
- supported self-assessments. In many cases, and assuming the assessment document is in an appropriately accessible format, people, perhaps with help from family members or advocates, could complete their own assessment form. Where existing online systems are available these should reflect any new assessment document options (see paragraphs 6.3 and 6.44 in the care and support statutory guidance)
- assessments using the telephone or, if possible, other technology such as video calls, if available, if people are comfortable with this, and if they can be made available at the location where people are living (see paragraph 6.3 in the care and support statutory guidance). Further guidance on this is provided by NHSx

The local authority should ensure that it is explained to people at the earliest opportunity that at some future point their needs may be assessed (or reassessed) and alternative services may be arranged. It should be explained that the current context is extremely unusual and that arrangements may be temporary and change when this period is over.

It will be important to explain to people that at a future point a view will be taken on whether their needs are eligible under the Care Act. This may mean that at a future date the local authority may no longer believe it is necessary to meet those needs, and that if this is the case, it will be necessary to agree alternative arrangements.

Local authorities need to ensure that there is a clear and transparent pathway for people with care and support needs, carers, advocates and providers to quickly raise concerns should they believe either the decision or the care package is in breach of the ECHR.

Complaints and escalation procedures remain the same as under the Care Act. Under the Coronavirus Act, once the emergency period has ended, if local authorities do not comply with their duty to carry out a relevant assessment within a reasonable period, action can be taken in court.

Care planning and delivery by providers

Care planning should be person led, person centred and proportionate to the complexity of individual need with paperwork, bureaucracy and process kept to a minimum, while ensuring adequate records are kept.

The easements relieve local authorities of the duty to prepare pre-amendment Care Act-compliant care and support plans.

However, local authorities should provide sufficient information to potential providers to allow them to make an informed decision as to whether to accept a referral. This decision should consider whether they can meet people's needs and comply with their own legal obligations. This will also help providers in drawing up their own plan for people's care and support. This information should be evidenced within whatever form of assessment is completed and there is a clear expectation that this information is shared with individuals, advocates and families.

The local authority should ensure that providers receive enough information to develop a care plan with the person. This should give an overview of the person's wishes and feelings, and outcomes that need to be considered and achieved. Information on key aspects of daily living, personal care, nutrition and hydration needs as well as any other medical conditions should be shared. Specific care needs that the provider will need to consider are also important such as communication, mobility and behavioural, cognitive and mental health needs. The assessment should also consider and share any safeguarding concerns and risk assessments. The assessment provided should enable the care provider to develop an appropriate care and support plan.

Local areas may choose to agree a minimum standard that local authorities and care providers should work towards and which reflects their local situation.

Decision-making about personal budgets, including direct payments, and care plans should be kept as close to the front line as possible with minimum restraints on flexibility and innovation in how needs can be met. Restrictive administrative practice should be avoided as much as possible.

The easements relieve local authorities of the duty to revise care and support plans under s27 of the Care Act during this period. However, subsection (2) and (3) remain in force, meaning that if local authorities choose to revise care and support plans during this period, they should continue to involve people who use services, advocates and carers in decisions about revising their care package. This may include unscheduled reviews where needs have changed. Local authorities will have to consider how they respond to reviews where need has significantly changed alongside the ethical framework for adult social care and the prioritisation guidance (see annex C below). These reviews may be more important than new assessments. However, local authorities should continue to comply with pre-amendment duties under s27 as far as it is reasonably practicable to do so. Reviews may need to be conducted in similar ways to assessments.

Local authorities and providers should work together to agree the circumstances in which, and by how much, the care package and direct payments can be varied without review to ease administrative burdens on the workforce. See further guidance on direct payments.

Financial assessment easements and retrospective charging

The easements enable local authorities to meet people's care and support needs without a financial assessment of their means. The legislation enables local authorities to conduct assessments at a later date and to retrospectively charge for meeting needs subject to those assessments, so long as the local authority informs people that there may be a charge at the time when the service is carried out, or before the service is carried out.

None of the fundamental principles underpinning the Care Act statutory guidance on charging and financial assessment (see paragraphs 8.2 to 8.9 of the care and support statutory guidance) are removed or diluted. Therefore, if people are charged retrospectively, this should be on the basis of a financial assessment in line with the Care Act and on the basis that people should pay what they can afford, and any charges are clear and transparent.

Local authorities should always ensure there is sufficient information and advice available in suitable formats to help people understand any financial contributions they are asked to make, including signposting to sources of independent financial information and advice. This will be especially important if easements are used and will be critical to helping people understand potential future costs, particularly when they may already be anxious and needing as much reassurance as possible.

Social workers, or others providing this information, should also consider what information can be given to illustrate estimated likely charges for different options of relevant and appropriate care so that people have a good initial understanding of the type and range of costs involved. This could take the form of a table, with tailored cost information based on illustrative averages, and form part of an upfront declaration or agreement.

Local authorities are always expected, where appropriate, to consult and engage with family members, advocates and/or someone who has legal authority to make

financial decisions on behalf of people who lack capacity. This consultation and engagement should still take place as part of the financial assessment, which may be deferred until after the emergency period. Where the financial assessment is deferred in this way, it will be important as a minimum, to make people aware that there may be costs associated with the care and support provided. Individuals should be assured that no charges will be made until after a financial assessment has been completed.

The existing statutory guidance (see 8.22 of the care and support statutory guidance) already notes that a local authority may 'choose to treat a person as if a financial assessment had been carried out'. The local authority must satisfy itself on the basis of evidence that the person can afford, and will continue to be able to afford, any charges due. This is known as a 'light touch financial assessment' and local authorities may wish to conduct more of these types of financial assessment where doing so helps the prioritisation of timely care and support and mitigates capacity pressures. Where appropriate or helpful, local authorities can use Department of Work and Pensions data as a quick standard assessment and follow up at a later date to look into private pensions, capital or other finances.

The existing statutory guidance (see 8.50 of the care and support statutory guidance) makes it clear that local authorities are not required to charge carers for support and that, 'in many cases it would be a false economy to do so'. Carers already play a vital role in the care and support system and their contribution during this emergency period will be even more critical. In line with existing guidance, local authorities should therefore 'ensure that any charges do not negatively impact on a carer's ability to look after their own health and wellbeing and to care effectively and safely'.

The emergency provisions do not change existing guidance on, for instance, complaints, deliberate deprivation of assets, administrative fees and top-ups.

Deferred payment agreements (DPAs) will still be made available for eligible people once the financial assessment is completed at a later date. DPAs do require some financial information to enable local authorities to be sure they are not taking on an unsecured risk and to place a legal charge on a person's property. DPAs should be raised as part of routine sharing of relevant information and advice.

Annex C: prioritisation process

Guidance on the prioritisation and timeliness of the delivery of adult social care under the Care Act easements

Local authority ASC departments will be well practised in responding to emergencies, where there is an incident or provider failure that results in the need to provide rapid support. On occasion, they may have to prioritise the delivery of such support to ensure those most in need and at highest risk receive this support as a priority.

This guidance must be read in conjunction with the ethical framework for adult social care.

The current challenge that local authorities face with COVID-19 means that prioritisation may need to be considered over a longer period with rapidly changing scenarios.

This guide has been produced to provide a helpful tool for ASC when considering how to prioritise care and support should the local authority have decided that it needs to operate under the Care Act easements. It is vital that professional judgement and oversight is used, as this document will not provide answers about prioritisation in all scenarios. It aims to help delivery of care and support in a risk-informed way, ensuring everyone, where possible, gets the care and support they require, but that those most in need are prioritised first.

Social care is a locally delivered and led service developed on the detailed understanding of individuals and their families and advocates, communities and cultures. Social workers, occupational therapists, and nurses form the core professional group therefore have clear professional responsibilities and accountabilities. Local professional leaders such as PSWs and principal occupational therapists will be key in ensuring this guidance is applied and understood. The skill of these professionals should be used to help develop, agree and review locally agreed processes that would be informed by this guidance.

Understanding local care needs and prioritisation

Base principle

Most local authorities will have mapped all existing known packages for complexity and need and should where possible have also mapped the care and support needs of those that self-fund.

It is important that mapping at this stage considers the complexity, risk and level of need within the care package and not just the current delivery. This should allow for a better understanding of the risk should there be an impact on care delivery. This includes considering unpaid carers. This will ensure local authority knowledge of an individual informs any prioritisation work needed, should the situation require it.

Local authorities may want to 'RAG-rate' their packages and have them split between high, moderate and low (or similar terminology). It is likely that many will have a mixed care package. They should note these but work on the most essential element of care for mapping purposes.

Prioritisation

If operating under the Care Act easements, local authorities may need to prioritise packages of care and support. In the first instance local authorities would consider those care packages which are already mapped and noted as high and moderate. Prioritising individual care may be fluid, as risk and need levels may fluctuate. New information such as unpaid carer involvement or whether people have now become unwell with COVID-19 will need to be considered.

DHSC does not propose to advise local areas on how to prioritise as methods of prioritisation will be unique to each area. The Department also recognises that there will already be well established methods of prioritising in most areas.

As set out in the guidance and ethical framework for adult social care, local authorities must retain an approach to working with individuals and carers in a personalised and effective way, ensuring they are engaged in this process as much as possible.

Local authorities should take into account all elements of a person's life that may impact on their needs and their personal circumstances. These circumstances can include social issues such as domestic abuse, financial issues and the vital support of unpaid carers which may not be appropriate or sustainable as a single support in this current climate.

Local authorities should also understand what resources, assets/offers the person has at their disposal, including knowledge of and access to forms of community and neighbourhood support.

Annex D: safeguarding guidance

Adult safeguarding is working with adults with care and support needs to support them to keep safe from abuse or neglect. It is an important part of what many public services do, and a statutory responsibility of local authorities.

Safeguarding adults remains a statutory duty of local authorities to keep everyone safe from abuse or neglect. The Coronavirus Act 2020 does not affect the safeguarding protections in the Care Act, particularly at section 42 of the Care Act. It is vital that local authorities continue to offer the same level of safeguarding oversight and application of section 42. However, it is also important that safeguarding teams are proportionate in their responses and mindful of the pressure social care providers are likely to be under.

The government recognises that safeguarding concerns and referrals may increase during the COVID-19 outbreak, with more people receiving support and support needs changing, which may prompt concerns. Safeguarding is everyone's business, so it is important that we remain alert to possible abuse or neglect concerns. Local authorities, social care providers, the health voluntary sector and our communities must continue work to prevent and reduce the risk of harm to people with care and support needs, including those affected by COVID-19.

The immediate safety of the adult at risk and their carers must always be prioritised but where decisions are taken to prioritise responses to safeguarding concerns, the PSW or safeguarding lead will advise. PSWs must work with their safeguarding leads to review any local policies or procedures that may be unduly time-consuming or place an undue burden on care providers during this time. For example, local authorities may make changes to those local processes and timescales that are not mandated by legislation. In addition, PSWs should reassure themselves that section 42 decision-making is proportionate and that safeguarding teams are actively communicating with partners. Any such decision will have been agreed by the director of adult social services.

The ethical framework for adult social care provides support to ongoing response planning and decision-making to ensure that ample consideration is given to a core set of ethical values and principles when organising and delivering social care for adults, including for safeguarding.

All providers of adult social care or health care have a key role in safeguarding adults in their care, and all agencies have a duty to ensure adults with care and support needs are not placed at risk of abuse or neglect by delays in care and support planning.

Employers must ensure that staff, including volunteers, are trained in recognising the signs and symptoms of abuse or neglect, how to respond, and where to go for advice and assistance.

Annex E: link to the Coronavirus Act 2020 explanatory notes

Coronavirus Act 2020 explanatory notes.

Appendix 2: Participant Recruitment and Survey Distribution

Recruitment of Principal Social Workers and Safeguarding Leads was undertaken via email invitation. Recruitment of carers was supported by the projects two partner organisations, Together in Dementia Everyday (tide) and Making Space, both national charities supporting unpaid carers of people living with dementia, who shared information about the study with carers across their networks via email, social media, and printed flyers. Information about the study was similarly shared by numerous national and local third sector organisations, who distributed and cascaded information across their members and networks. The study was listed as a research opportunity on VOICE and Join Dementia Research (JDR), and an email invitation was sent to all carers matching the study criteria on the JDR database. The NIHR Clinical Research Networks adopted the study for recruitment to the survey arm, led by Manchester Clinical Research Network.

Recruitment of interviewees began in April 2021 when many services and support groups remained closed, suspended, or online. Contacting carers was subsequently challenging as many of the usual avenues for sharing information about the opportunity to participate were unavailable. Ultimately, JDR provided the most successful resource for recruitment of carers to the interview arm of the study and also provided substantial recruitment to the survey, with 20 per cent of survey respondents recruited via JDR.

Recruitment to the survey took place from April to June 2022. Local Clinical Research Networks (LCRNs) around the country shared a link to the online survey and distributed paper surveys to appropriate networks of carers and to carers directly. Thirteen NHS sites (listed below) agreed to act as Participant Identification Centres (PICs) for the survey, employing various means of identifying family carers of people living with dementia at home including direct mailings where they had contact information, and distribution of online links and flyers as well as paper surveys to caregiver networks and other local organisations. The LCRNs provided 28 per cent of survey respondents.

Despite targeted approaches, carers from black and minority ethnic backgrounds remain underrepresented in the interview arm of the study, which is a notable limitation given the increased risk for Covid morbidity and mortality for minoritised ethnic groups. We did not collect information about ethnicity in the survey as due to anticipated sample sizes we did not have a reasonable prospect of being able to distinguish statistics for any ethnic group, thus could not justify collecting this personal information.

We are very grateful to the organisations that kindly shared information about the research project and/or supported the distribution of the survey including (in alphabetical order):

- ADASS including the regional networks
- African Caribbean Care Group
- Age UK and local branches including Age UK Sunderland, Age UK Oldham and Age UK Staffordshire
- Alzheimer's UK
- Better Understanding of Dementia for Sandwell (BUDS)
- Birmingham Carers Hub
- CARE75+
- Carers Manchester
- Carers Trust Heart of England
- Carers UK
- Dementia United
- Derbyshire Carers Association
- Gaddum
- Greater Manchester Health & Social Care Partnership
- Greater Manchester Older Peoples Network
- Humphrey Booth Resource Centre
- Join Dementia Research
- Manchester Carers Forum
- Making Space
- Manchester Institute for Collaborative Research Ageing
- Positive Mental Health Network Newsletter
- Sunderland Carers Centre
- The Essence Service
- Together in Dementia Everyday (tide)
- VOICE
- Wakefield Memory Action Group

Via Local Clinical Research Networks (LCRNs) and NHS Sites (in alphabetical order):

- Avon and Wiltshire Mental Health Partnership NHS Trust
- Berkshire Healthcare NHS Foundation Trust
- Black Country Healthcare NHS Foundation Trust
- Birmingham and Solihull Mental Health Foundation Trust
- Birmingham Community Healthcare
- Cumbria County Council
- Derbyshire Healthcare NHS Foundation Trust
- East Coast Community Healthcare CIC
- Hammersmith and Fulham Council
- LCRN Manchester
- LCRN West Midlands Core Team
- Leicestershire Partnership NHS Trust
- Lincolnshire Partnership NHS Trust
- Mersey Care NHS Foundation Trust
- Norfolk Community Health and Care NHS Trust
- Norfolk and Suffolk NHS Foundation Trust
- Royal United Hospitals Bath NHS Foundation Trust
- School of Health & Social Care, University of Lincoln
- South West London & St George's Mental Health NHS Trust/Springfield University Hospital
- Wirral Community Health and Care NHS Trust

Appendix 3: Carer interviewee characteristics

Interview number	Local Authority area	Carer gender	Carer age	Approx. year partner's diagnosis	PLWD age	Dementia type
1	Easement	Female	72	2013	72	FTD
2	Non-easement	Male	82	2017	82	Vascular
3	Easement	Female	73	2014	74	Mixed
4	Easement	Female	77	2004	80	Alzheimer's
5	Non-easement	Female	85	2018	84	Alzheimer's
6	Non-easement	Female	75	2018	90	Alzheimer's
7	Non-easement	Male	77	2017	76	Alzheimer's
8	Non-easement	Male	77	2016	73	Alzheimer's
9	Non-easement	Female	72	2016	78	Alzheimer's
10	Non-easement	Female	73	2017	77	Alzheimer's
11	Easement	Male	70	2014	72	Mixed
12	Easement	Male	83	2021	81	Alzheimer's
13	Non-easement	Male	77	2020	78	Unknown
14	Easement	Male	80	2017	76	Mixed
15	Easement	Male	80	2018	80	Mixed
16	Non-easement	Female	74	2016	77	Vascular
17	Non-easement	Female	75	2019	73	Vascular
18	Easement	Female	73	2018	72	Alzheimer's
19	Non-easement	Male	71	2012	71	Alzheimer's
20	Easement	Female	82	2017	85	Mixed
21	Non-easement	Female	73	2019	73	Mixed
22	Non-easement	Female	77	2014	82	Alzheimer's
23	Easement	Female	85	2018	86	Mixed
24	Non-easement	Female	82	2018	80	Alzheimer's
25	Easement	Female	82	2018	82	Alzheimer's
26	Non-easement	Female	70	2021	80	Mixed
27	Non-easement	Female	70	2020	70	Mixed
28	Non-easement	Male	74	2018	72	Alzheimer's

Interview number	Local Authority area	Carer gender	Carer age	Approx. year partner's diagnosis	PLWD age	Dementia type
29	Non-easement	Female	75	1999	77	Vascular
30	Non-easement	Female	80	2017	77	Mixed
31	Non-easement	Female	75	2019	88	Alzheimer's
32	Easement	Female	76	2020	77	Other
33	Non-easement	Female	74	2022	74	FTD
34	Easement	Female	76	2017	76	Alzheimer's
35	Non-easement	Female	86	2021	88	Unknown
36	Easement	Female	76	2021	85	Alzheimer's
37	Non-easement	Male	76	2015	75	Alzheimer's
38	Non-easement	Male	86	2014	86	Mixed
39	Easement	Male	76	2018	75	Alzheimer's
40	Easement	Female	73	2017	73	Other
41	Easement	Male	77	2018	76	Other
42	Non-easement	Male	72	2020	75	Alzheimer's
43	Non-easement	Male	76	2017	62	Young Onset
44	Non-easement	Female	75	2015	82	Mixed
45	Non-easement	Female	72	2021	90	Mixed
46	Non-easement	Female	80	2017	89	Vascular
47	Easement	Male	78	2017	76	Alzheimer's
48	Non-easement	Female	77	2018	87	Alzheimer's

Appendix 4: Spradley's Semantic Relationships Table

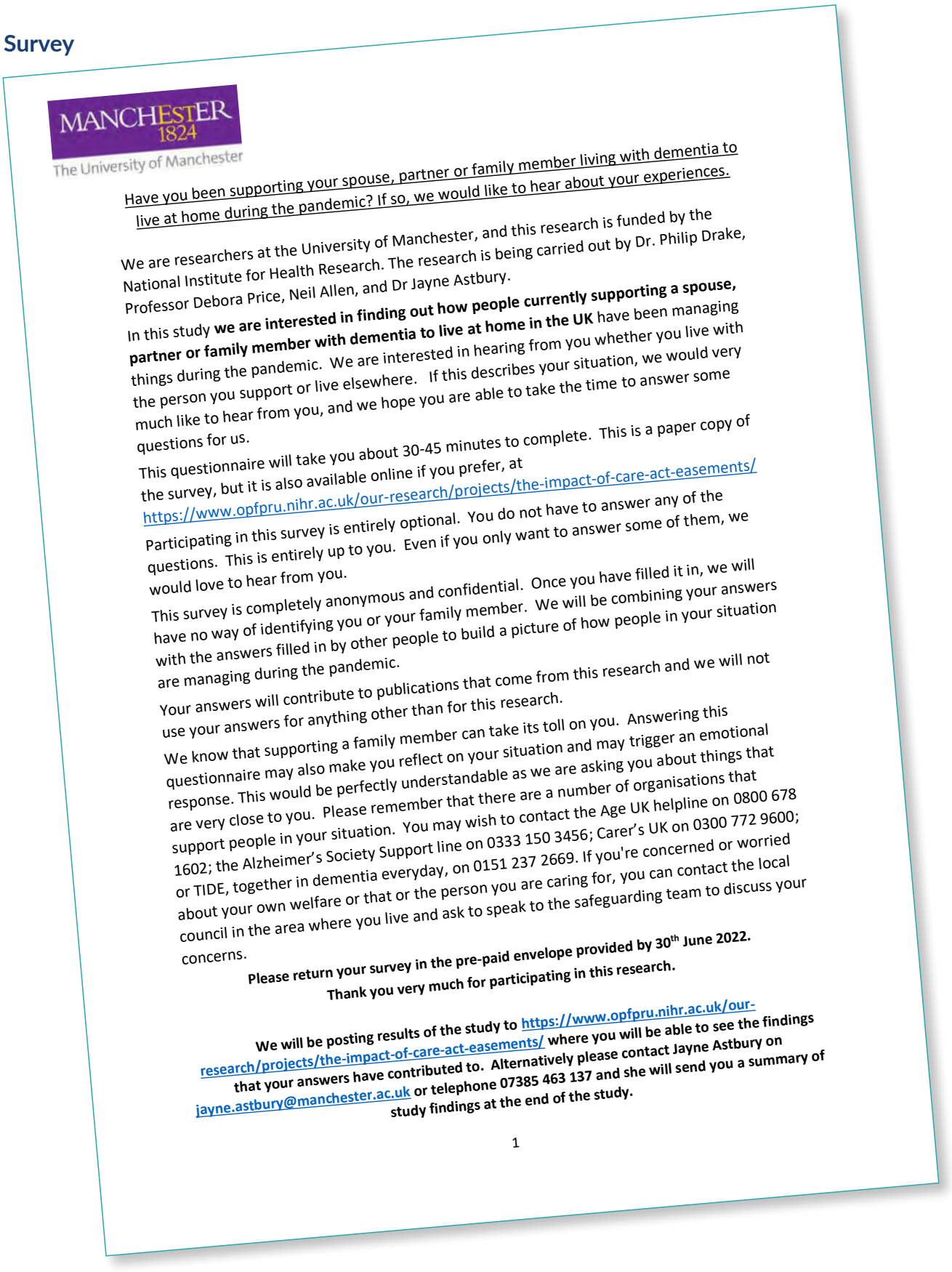
Spradley's Nine Universal Semantic Relationships

From: James P Spradley (1979) *The Ethnographic Interview.* Holt, Rinehart and Winston. Page 111.

1.	Strict inclusion	X is a kind of Y
2.	Spatial	X is a place in Y, X is a part of Y
3.	Cause-effect	X is a result of Y, X is a cause of Y
4.	Rationale	X is a reason for doing Y
5.	Location for action	X is a place for doing Y
6.	Function	X is used for Y
7.	Means-end	X is a way to do Y
8.	Sequence	X is a step (stage) in Y
9.	Attribution	X is an attribute (characteristic) of Y

Appendix 5: Survey and Technical Details

Survey



MANCHESTER 1824
The University of Manchester

Have you been supporting your spouse, partner or family member living with dementia to live at home during the pandemic? If so, we would like to hear about your experiences.

We are researchers at the University of Manchester, and this research is funded by the National Institute for Health Research. The research is being carried out by Dr. Philip Drake, Professor Debora Price, Neil Allen, and Dr Jayne Astbury.

In this study **we are interested in finding out how people currently supporting a spouse, partner or family member with dementia to live at home in the UK** have been managing things during the pandemic. We are interested in hearing from you whether you live with the person you support or live elsewhere. If this describes your situation, we would very much like to hear from you, and we hope you are able to take the time to answer some questions for us.

This questionnaire will take you about 30-45 minutes to complete. This is a paper copy of the survey, but it is also available online if you prefer, at https://www.opfpru.nihr.ac.uk/our-research/projects/the-impact-of-care-act-easements/

Participating in this survey is entirely optional. You do not have to answer any of the questions. This is entirely up to you. Even if you only want to answer some of them, we would love to hear from you.

This survey is completely anonymous and confidential. Once you have filled it in, we will have no way of identifying you or your family member. We will be combining your answers with the answers filled in by other people to build a picture of how people in your situation are managing during the pandemic.

Your answers will contribute to publications that come from this research and we will not use your answers for anything other than for this research.

We know that supporting a family member can take its toll on you. Answering this questionnaire may also make you reflect on your situation and may trigger an emotional response. This would be perfectly understandable as we are asking you about things that are very close to you. Please remember that there are a number of organisations that support people in your situation. You may wish to contact the Age UK helpline on 0800 678 1602; the Alzheimer's Society Support line on 0333 150 3456; Carer's UK on 0300 772 9600; or TIDE, together in dementia everyday, on 0151 237 2669. If you're concerned or worried about your own welfare or that or the person you are caring for, you can contact the local council in the area where you live and ask to speak to the safeguarding team to discuss your concerns.

Please return your survey in the pre-paid envelope provided by 30th June 2022.

Thank you very much for participating in this research.

We will be posting results of the study to https://www.opfpru.nihr.ac.uk/our-research/projects/the-impact-of-care-act-easements/ where you will be able to see the findings that your answers have contributed to. Alternatively please contact Jayne Astbury on jayne.astbury@manchester.ac.uk or telephone 07385 463 137 and she will send you a summary of study findings at the end of the study.

1

BEGIN THE SURVEY

1) Do you currently support a spouse, partner or other family member with dementia **to live at home?** You may live with the person you support or live elsewhere.

Yes ☐ No ☐

If no, please do **not** continue. We know that your experience is important, and we are very sorry but unfortunately this study is limited to people who are supporting someone to live at home with dementia. If you know anyone in this position, please do pass this survey on to them.

2) Are you: Male ☐ Female ☐ I identify differently (please state) _____

3) Is the person that you support:
Male ☐ Female ☐ Identifies differently (please state) _____

4) How old are you? _____

5) And how old is your family member living with dementia? _____

6) How is the person living with dementia related to you?
They are my:

☐ Spouse
☐ Partner
☐ Parent
☐ Brother or sister (include adopted, half- & step-siblings)
☐ Child
☐ Other (please state) _____

7) Do you live with the family member with dementia that you support, or do you live elsewhere?

☐ Yes, we live in the same household
☐ We live on the same property but in different households (e.g. an annexe or separate flat)
☐ No, I live elsewhere [Please go to Q9]
☐ I live elsewhere, although I sometimes/often stay overnight with them [Please go to Q9]

8) If you live with the person with dementia that you support, does anyone else live with the two of you? (please tick all that apply)

No, it is just the two of us ☐ [Please go to Q10]

Yes:
☐ My spouse or partner
☐ My child or children
☐ Other (Please state who) _____
☐ Their spouse or partner
☐ Their child or children

9) If you live elsewhere, does the person with dementia that you support have anyone else living with them all the time in their household?

No, they live alone ☐

Yes:
☐ Their spouse or partner
☐ Their child or children
☐ A live in carer
☐ Other (Please state who) _____

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10) From your perspective, when did you learn that your family member has dementia? This doesn't need to be precise, just a rough estimate.

- ☐ Never been diagnosed
- ☐ Less than a year ago
- ☐ 1 – 2 years
- ☐ 3 – 4 years
- ☐ More than 4 years
- ☐ Don't know/not sure/can't remember

11) How long do you believe your family member's dementia has affected you as a carer? This may be longer than any formal diagnosis – we are asking here what you think the situation is. Again, it doesn't need to be precise, just roughly what you think the situation is.

- ☐ Less than a year
- ☐ 1 – 2 years
- ☐ 3 – 4 years
- ☐ More than 4 years
- ☐ Don't know/not sure/can't remember

12) Do you think your caring role is impacted by other conditions that your family member has in addition to dementia? Please tick all that apply:

- ☐ A physical disability
- ☐ Sight loss
- ☐ Hearing loss
- ☐ A mental health problem
- ☐ Mobility problems
- ☐ Problems connected to ageing
- ☐ A learning disability or difficulty
- ☐ Terminal illness
- ☐ Alcohol or drug dependency
- ☐ Other condition (please state) _____
- ☐ None of these

13) And do you have any of these conditions? Please tick all that apply.

- ☐ High blood pressure or hypertension
- ☐ Angina, a heart attack, congestive heart failure
- ☐ Diabetes or high blood sugar
- ☐ A stroke
- ☐ Chronic lung disease such as chronic bronchitis or emphysema
- ☐ Asthma
- ☐ Arthritis including osteoarthritis or rheumatism
- ☐ Cancer, leukemia or a malignant tumour
- ☐ Visual impairment, blindness
- ☐ Hearing impairment, deafness
- ☐ Autism/ADHD/dyspraxia/neurodivergent
- ☐ Other condition (please state) _____
- ☐ None of these

Thank you for telling us about yourself and the person you support. We now want to ask you about the kinds of help and support that you might have and receive.

14) **Prior to the pandemic,** did **you** get support from any of the following people with providing care, everyday tasks or emotional support? *Please tick all that apply*.

	Help to care for my spouse, partner or family member	Everyday tasks like shopping, gardening, cleaning	Emotional support
My children			
My siblings			
My grandchildren			
My spouse			
Other relatives			
Friends			
Neighbours			
Community group or volunteers			
Religious organisation			
Organisation like Age UK or similar			

15) Prior to the pandemic, about how many hours per week, in an average week, were you provided with help or support from someone else? This does not have to be precise, we just want a general idea:
Hours per week: _____

16) **Prior to the pandemic beginning in March 2020**, did you have any of the following kinds of help for the support that you provide to the family member with dementia?
Please tick all that apply

- ☐ Social worker
- ☐ Admiral Nurse
- ☐ Helpline (say which: _____)
- ☐ Counsellor/therapist
- ☐ GP or community mental health services
- ☐ Group activity for my family member with dementia
- ☐ Group activity for me without my family member with dementia
- ☐ Group activity for the two of us together
- ☐ Befriending or visiting service
- ☐ Home care or domiciliary care
- ☐ Meals on wheels /Cleaner /Laundry Service
- ☐ Sitting service
- ☐ Respite days in a residential home
  If yes, how often? _____
- ☐ Day Centre days
  If yes, how many days per week? _____
  How many hours each day? _____
- ☐ Lunch Club visits
- ☐ Other (please state) _____

☐ None of the above [If none of these, please go to Q18]

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17) If your answer to any of the above was **yes**, how were these services paid for? Please tick **all** that apply, e.g. if some were paid by the family and some by the local authority, tick both boxes

- ☐ The person with dementia paid for these services, either alone or with their spouse or partner
- ☐ The services were paid for privately by the wider family
- ☐ By the local authority
- ☐ By a charity or free of charge
- ☐ Don't know/not sure

18) Are you or your family member with dementia in receipt of any of the following benefits to help pay for any costs of care? Please tick all that apply

- ☐ NHS Continuing Health Care
- ☐ Carer's allowance
- ☐ Disability Living Allowance
- ☐ Personal Independence Payment
- ☐ Carer premium
- ☐ Attendance Allowance
- ☐ Other (please state) _____
- ☐ Don't know/Not sure

19) Have **your family member's** needs for care ever been formally assessed by the Local Authority? If yes, please answer based on the last assessment carried out.

- ☐ Yes, before March 2020 (before the pandemic started)
- ☐ Yes, since the pandemic started (since March 2020)
- ☐ No, never assessed
- ☐ Don't know/Not sure

20) Have **your needs for support as a carer** ever been formally assessed by the Local Authority? If yes, please answer based on the last assessment carried out.

- ☐ Yes, before March 2020 (before the pandemic started)
- ☐ Yes, since the pandemic started (since March 2020)
- ☐ No, never assessed
- ☐ Don't know/Not sure

Thank you for telling us about the situation prior to the pandemic. We now want to ask you about your experiences during the pandemic:

21) Were you or your family member contacted by the NHS or GP and advised that you are vulnerable and at risk of severe illness if you catch Covid-19 and should stay at home at all times and avoid any face-to-face contact? (Advised to shield)

☐ Yes I was ☐ Yes my family member was ☐ Yes we both were ☐ No, neither of us

22) In this question:
Self-isolating means not leaving your household at all for any reason
Staying at home means only leaving your house for limited purposes such as shopping for food, exercise, or essential trips

During the pandemic overall, would you say **your family member with dementia** and **you** have been:	Your family member	You
Mostly self-isolating	☐	☐
Mostly staying at home	☐	☐
A mixture of self-isolating and staying at home	☐	☐
Mostly neither self-isolating nor staying at home	☐	☐

23) Does your family member need someone to be with them? Please tick the box that most closely fits your situation:

☐ Yes, 24 hours a day
☐ Most of the time, although they can be left for short periods e.g. less than an hour
☐ Much of the time but they can be left alone for a few or several hours
☐ They can be left alone for stretches of time but need oversight/help several times a day
☐ They can be left alone for stretches of time but need oversight/help once or twice a day
☐ They only need someone with them during the night
☐ No, they do not need someone with them

24) **In the past week**, on how many days did you personally have to deal with the following things?

On how many days did your family member:	Not at all	1 – 2 days	3 – 4 days	5+ days
Keep you up at night				
Repeat questions/stories				
Try to dress the wrong way				
Have a bowel or bladder "accident"				
Hide belongings and forget about them				
Cry easily				
Act depressed or downhearted				
Cling to you or follow you around				
Become restless or agitated				
Become irritable or angry or aggressive				
Swear or use foul language				
Become suspicious, or believe someone is going to harm them				
Tried to leave the home at the wrong time/when it is not safe				
Show sexual behaviour or interest at the wrong time or place				
Other (please say) _____				

25) These are things that many people in similar situations to you report feeling from day to day. Tick the box if this is true for you.

- ☐ Do you ever feel you can no longer cope with the situation?
- ☐ Do you ever feel you need a break?
- ☐ Has your own health suffered at all?
- ☐ Do you worry about accidents happening to your family member?
- ☐ Do you ever feel that there will be no end to the problem?
- ☐ Do you ever feel embarrassed by your family member?
- ☐ Do you ever get cross or angry with your family member?
- ☐ Do you ever feel frustrated at times with your family member?
- ☐ Do you feel alone in what you are going through?
- ☐ Do you have financial fears for the future?

26) Has the amount of support **<u>you</u> provide for your family member** changed since the Coronavirus outbreak?

☐ It has increased ☐ It has decreased ☐ It has stayed the same

27) **Thinking of the last week**, about how many hours in the week were you needing to be there to provide help or support to your family member:

☐ More than 30 ☐ 10 to 20

☐ More than 20 up to 30 ☐ Less than 10

28) Since the pandemic began, has the amount of support you get from any of the following people with care, everyday tasks or emotional support **changed**? Do you now get:

	I never got this form of support	…more support	…the same amount	…somewhat less support	…much less support	… no or almost no support
My children						
My siblings						
My spouse						
My grandchildren						
Other relatives						
Friends						
Neighbours						
Community group or volunteers						
Religious organisation						
Organisation like Age UK or similar						

29) Since the pandemic began, has the amount of help or support **you yourself** get from any of the following sources **changed**? Do you now get:

	I never got this form of support	…more support	…about the same	… less support	… no or almost no support
Social worker					
Admiral Nurse					
Helpline (say which: _____)					
Counsellor or therapist					
GP or community mental health services					
Group activity for my family member with dementia and/or me					
Befriending or visiting service					
Home care or domiciliary care					
Meals on wheels/Cleaner/Laundry Service					
Sitting service					
Respite days in a residential home					
Day Centre days					
Lunch Club visits					
Other (please state) _____					

30) Where help or support stopped completely for much or all of the time, why did this happen? (please tick **all** that apply):

☐ We did not want that person or service coming into the house during the pandemic

☐ That person did not want to or did not feel they could or should come into our house during the pandemic

☐ We did not want to participate in activities outside the home during the pandemic

☐ The service provider notified us that the service would no longer be available because of the pandemic

☐ The residential home or day centre was closed to us

☐ We found the changes in the service were such that it was no longer useful to us

☐ We were anxious that the service was not safe during the pandemic

☐ We did not need the service anymore

☐ Other (please state)_____

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31) Was your family member in receipt of some support face to face before the pandemic that changed to online provision as a result of the pandemic, for example a group activity, support from the day centre or social care support?

☐ Yes ☐ No ☐ Don't know

If yes, how did you and your family member find the online provision?

☐ It was better than the face to face provision for both of us
☐ It was as good as the face to face provision for both of us
☐ It was as good as the face to face provision for my family member but worse for me
☐ It was worse than the face to face provision for my family member but better for me
☐ It was worse for both of us

Thank you for answering these questions about help and support for your family member during the pandemic. We would now like to ask you some questions about whether any professionals have been supporting you for yourself.

32) Since the pandemic began, have you **wanted** to see or talk to a GP?

☐ Yes ☐ No

If yes, have you **been able** to see or talk to a GP?

☐ Yes ☐ No, but I tried ☐ I did not attempt to contact them

33) Since the pandemic began, have you contacted **anyone** asking for help in your caring role?

☐ Yes ☐ No

If yes, who did you contact? _____

(e.g. was this a friend, family members, local authority, health professional, charity etc)

If yes, did you feel you received the help that you needed from them? ☐ Yes ☐ No

34) Since the pandemic began in March 2020, has your family member with dementia had a medical assessment from the GP, hospital or community medical team assessing the progress of their dementia and their needs?

☐ Yes ☐ No ☐ Don't know/not sure

35) Since the pandemic began, has anyone from a service, agency or the local authority contacted **you** to find out how **you** are managing?

☐ Yes ☐ No

If yes, how often have you been contacted?

☐ Weekly
☐ A few times a month but less than weekly
☐ Once a month
☐ Less than once a month but a few times in a year
☐ Once or twice a year
☐ More than a year ago and not since

If yes, did you find the contact helpful?

☐ Yes ☐ No ☐ Hard to say/Not sure

36) **In the past month**, how often have you done the following with any of your immediate family (parents, children, grandchildren and brothers and sisters) not counting any who live with you?

	Daily	3–6 times a week	Once or twice a week	Less than once a week	Not at all in the last month
Speak on the phone					
Video-calling (e.g. Skype, FaceTime)					
Write or email					
Send or receive text messages					

37) **In the past month**, how often have you done the following with other relatives or friends?

	Daily	3–6 times a week	Once or twice a week	Less than once a week	Not at all in the last month
Speak on the phone					
Video-calling (e.g. Skype, FaceTime)					
Write or email					
Send or receive text messages					

Thank you for answering questions about the support and help you received before and during the pandemic. The next section asks questions about how you are feeling in yourself, including whether you might be feeling isolated or depressed. We are asking these questions because we want to know whether carers in your situation are experiencing these feelings, so that we can report on this issue. At the end of the survey we have some information about organisations you can contact for support, which we hope might be helpful.

38) In the past month would you say your health was:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

39) Do any of the following apply to you?

	Agree strongly	Agree	Disagree	Disagree strongly
I regularly have to do things as a carer that I am not comfortable with				
Almost all of my conversations are about dementia or caring				
People see me only as a carer rather than a person in my own right				
It is hard to find anyone else to spend time looking after the person I care for				
I dread the future				
I can only get through one day at a time				
My role in our relationship has changed				
Receiving help is more hassle than it's worth				
I have to cope with a lot of opinions about what I should and shouldn't do				

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	Agree strongly	Agree	Disagree	Disagree strongly
There is always something new to deal with when providing care				
Little things add up to make caring difficult				
I don't take very good care of myself				
I often feel I want to escape my caring responsibilities				
Caring for my family member with dementia prevents me from fulfilling my other caring responsibilities				
I feel guilty if I do something for myself				
I find it hard to find time for myself				
I would like it if others tried harder to understand the situation I am in				
Everything I do has to be planned in advance now				
I spend a lot of time trying to sort out services				
It is too challenging trying to sort out services				
I have given up trying to sort out services				

40) Over **the last two weeks**, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge				
Not being able to stop or control worrying				
Worrying too much about different things				
Trouble relaxing				
Being so restless it is hard to sit still				
Becoming easily annoyed or irritable				
Feeling afraid as if something awful might happen				

41) Now think about the past week and the feelings you have experienced. Answer yes if the following was true for you **much of the time during the last week**

For much of the time during the last week:	Yes	No
You felt depressed		
You felt that everything you did was an effort		
Your sleep was restless		
You were happy		
You felt lonely		
You enjoyed life		
You could not get going		
You felt exhausted		

42) The next questions are about how you feel about different aspects of your life.

For each one, please say how often you feel that way	Hardly ever or never	Some of the time	Often
How often do you feel you lack companionship?			
How often do you feel left out?			
How often do you feel isolated from others?			

Finally, we'd like to ask you a few questions about your current circumstances.

43) Does the property you are living in have any of the following:

- ☐ A garden
- ☐ A roof terrace
- ☐ Other private outdoor space e.g. balcony/concrete yard
- ☐ Other shared outdoor space
- ☐ None of these

44) How would you describe your financial situation?

- ☐ Living comfortably
- ☐ Doing all right
- ☐ Just about getting by
- ☐ Finding it quite difficult
- ☐ Finding it very difficult

45) Which country do you live in?

☐ England ☐ Scotland ☐ Wales ☐ Northern Ireland ☐ Other_____

46) Which local authority do you live in? _____

(We are asking this as we would like to be able to compare the experiences of people living in different local authorities. We will never use this information for any other purpose.)

47) On a scale of 0 to 10 where 0 is "not at all" and 10 is "very", how satisfied are you with your life nowadays? Please circle your answer.

0.....1.....2.....3.....4.....5.....6.....7.....8.....9.....10

In your view, has anything good come out of the pandemic for you and your family member?

What has been the most difficult thing for you and your family member during the pandemic?

Is there anything else you would like to tell us? Please continue on a separate sheet if there is not enough space.

Thank you very much for participating in this study.

PLEASE NOW RETURN THIS SURVEY IN THE POSTAGE-PAID ENVELOPE PROVIDED

No stamp is needed, just drop it into a post-box.

Please note if you are in need of help and advice, the nationwide charity 'Carers UK' provides support and guidance on a wide range of issues.

Carers UK telephone helpline is available on 0808 808 7777 from Monday to Friday, 9am – 6pm. They can also be contacted by email on advice@carersuk.org. Further details can be found on https://www.carersuk.org/help-and-advice.

If you need somebody to talk to or a listening ear, Samaritans is also available 24 hours a day, 365 days a year on 116 123 or you can email jo@samaritans.org.

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Technical details

The survey recruited people supporting a family member to live at home with dementia, who were still doing so at the time of the fieldwork in April to June 2022. Eligibility for the survey was determined via the first survey question. There is no national database of family caregivers supporting people living with dementia to live at home and so no representative sampling frame exists. This was therefore necessarily, and in common with other carer surveys, a non-probability observational sample. [1,2] Routes to survey recruitment are detailed in Appendix 2, and utilised the Join Dementia Research network, a UK based national research registry for people with dementia and their carers, the NIHR Local Clinical Research Networks including 13 NHS Participant Identification Centres, and a large number of third sector and service organisations. The survey could be completed either online or in paper format, with paper surveys being returned via a Freepost envelope. As potential participants could be approached via generic newsletters, social media announcements and via existing and established networks with third sector organisations and service providers, no data on response rates is available.

In all, 622 people accessed the online survey of whom 543 proceeded past the participant information pages, and of those 451 met our primary criterion of currently supporting a family member living with dementia to live at home. We received 154 paper surveys back of whom 153 met this criterion. The data from online and paper surveys were merged into a single dataset of 604 respondents for analysis.

The survey was designed following analysis of in-depth carer and professional interviews and in close collaboration with our partner organisations and our older carer advisory group.

The survey collected demographic variables summarised in Appendix 6, including gender, age, living arrangements and health conditions of respondents and the family member living with dementia that they support, and length of time living with dementia. Data were also collected about the property lived in, country and local authority, and financial strain. Detailed information was collected of formal support and unpaid and family support received prior to the pandemic, including financing and assessments. The survey then proceeded to collect information about pandemic experiences including shielding and staying at home, detailed information about caregiving needs, changes in support both given and received, and reasons for, and experiences of, those changes. Data was collected about interactions with formal support and medical services during the pandemic.

The survey then collected a number of variables measuring health and wellbeing. These included:

- the Relatives Stress Scale[3]
- the 13 item 'problematic behaviour' question set[4]
- the recently developed SIDECAR Scale to measure quality of life of carers of people living with dementia: "SIDECAR: Scales measuring the Impact of Dementia on Carers".[5] The scale was developed in a project funded by the Medical Research Council and the National Institute for Health Research (NIHR). Grant title: HQLC Dementia Carers Instrument Development: DECIDE (MR/ M025179/1), with the *specific aim of developing a set of survey questions from the "bottom up" developed by and with carers of people living with dementia*.

1 See for example Clarissa Giebel et al., *A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers*, 36 Int. J. Geriatr. Psychiatry 393 (2021).

2 And the surveys referenced in Clarissa Giebel et al., *The early impacts of COVID-19 on unpaid carers of people living with dementia: part II of a mixed-methods systematic review*, https://doi.org/10.1080/13607863.2022.2084510 1 (2022), https://www.tandfonline.com/doi/abs/10.1080/13607863.2022.2084510 (last visited Aug 6, 2022).

3 J. G. Greene et al., *Measuring Behavioural Disturbance of Elderly Demented Patients in the Community and its Effects on Relatives: A Factor Analytic Study*, 11 Age Ageing 121 (1982), https://academic.oup.com/ageing/article/11/2/121/34308 (last visited Aug 18, 2022).

4 Rosanna M. Bertrand, Lisa Fredman & Jane Saczynski, *Are all caregivers created equal? Stress in caregivers to adults with and without dementia*, 18 J. Aging Health 534 (2006), https://journals.sagepub.com/doi/abs/10.1177/0898264306289620 (last visited Aug 18, 2022); Jane L. Givens et al., *Depressive Symptoms Among Dementia Caregivers: Role of Mediating Factors*, 22 Am. J. Geriatr. Psychiatry 481 (2014); Dr Argyroula Kalaitzaki et al., *Dementia Family Carers' Quality of Life and Their Perceptions About Care-receivers' Dementia Symptoms: The Role of Resilience.*, J. Aging Health 898264321105020 6 (2021), http://www.ncbi.nlm.nih.gov/pubmed/34664525 (last visited Aug 18, 2022).by treating caregivers as a homogenous group, it is possible that stress-related factors are misrepresented for some. This study of 349 elderly caregivers explored mediators of the caregiving/ stress relationship for caregivers to adults with (n = 106).

5 Mike C. Horton et al., *Measuring Quality of Life in Carers of People with Dementia: Development and Psychometric Evaluation of Scales measuring the Impact of DEmentia on CARers (SIDECAR)*, 61 Gerontologist E1 (2021).

- the Generalized Anxiety Disorder (GAD-7) questionnaire: a seven-item, self-report anxiety questionnaire designed to assess a person's anxiety during the previous 2 weeks. evaluating seven symptoms of anxiety, such as becoming easily annoyed or irritable or not being able to stop or control worrying, on a 4-point scale ("Not at all, "Several days", "More than half the days", "Nearly every day"). This is a well-validated tool, with a high scale reliability used to screen for generalised anxiety disorder in clinical practice and research. A standard threshold score of 10 on the GAD-7 scale was used to define clinically significant symptoms.[6]
- the 7-item CES-D scale used to measure symptoms of depression.[7] The CES-D scale is not a diagnostic instrument for clinical depression but can be used to identify people "at risk" of clinical depression in population-based studies. This short version has comparable psychometric properties to the full 20-item CES-D.[8] The scale includes 8 binary (no/yes) questions that ask whether respondents experienced any depressive symptoms, such as feeling sad or having restless sleep, in the week prior to interview. In line with convention, we classified respondents who reported four or more depressive symptoms on the CES-D scale as with elevated depressive symptoms.[9]
- the 3 item Revised UCLA Loneliness Scale.[10]
- social isolation using the ELSA social isolation measures, which measure frequency of contact with family and other relatives or friends on a 5 point scale with higher scores indicating higher social isolation.[11]
- self-rated health, measured using responses to a generic question on a 5-point ordinal scale
- life satisfaction as a measure of personal wellbeing using the Office for National Statistics wellbeing scale on a scale of 1 to 10. This measure allows respondents to integrate and weigh various life domains the way that they choose.[12]

Finally, the survey included three open-ended questions asking whether respondents felt anything good had come out of the pandemic for them, what the most difficult thing for them and their family member had been during the pandemic, and asking whether there was anything else they would like to tell us.

6 Robert L. Spitzer et al., *A brief measure for assessing generalized anxiety disorder: the GAD-7*, 166 Arch. Intern. Med. 1092 (2006), https://pubmed.ncbi.nlm.nih.gov/16717171/ (last visited Jun 26, 2022).

7 Jason C. Cole et al., *Development and validation of a Rasch-derived CES-D short form*, 16 Psychol. Assess. 360 (2004), /doiLanding?doi=10.1037%2F1040-3590.16.4.360 (last visited Aug 18, 2022); Stephen Z. Levine, *Evaluating the seven-item Center for Epidemiologic Studies Depression Scale short-form: a longitudinal US community study*, 48 Soc. Psychiatry Psychiatr. Epidemiol. 2013 489 1519 (2013), https://link.springer.com/article/10.1007/s00127-012-0650-2 (last visited Aug 18, 2022).

8 Jahanvash Karim et al., *Validation of the Eight-Item Center for Epidemiologic Studies Depression Scale (CES-D) Among Older Adults*, 34 Curr. Psychol. 681 (2015), https://link.springer.com/article/10.1007/s12144-014-9281-y (last visited Jun 26, 2022).

9 Carolyn L. Turvey, Robert B. Wallace & Regula Herzog, *A revised CES-D measure of depressive symptoms and a DSM-based measure of major depressive episodes in the elderly*, 11 Int. psychogeriatrics 139 (1999), https://pubmed.ncbi.nlm.nih.gov/11475428/ (last visited Jun 26, 2022).

10 C M Masi et al., *A Meta-Analysis of Interventions to Reduce Loneliness*, 15 Personal. Soc. Psychol. Rev. 219 (2011).

11 Andrew Steptoe et al., *Social isolation, loneliness, and all-cause mortality in older men and women*, 110 Proc. Natl. Acad. Sci. U. S. A. 5797 (2013), https://www.pnas.org/doi/abs/10.1073/pnas.1219686110 (last visited Aug 18, 2022).

12 William Pavot & Ed Diener, *Review of the Satisfaction With Life Scale*, 101 (2009), https://link.springer.com/chapter/10.1007/978-90-481-2354-4_5 (last visited Jun 26, 2022).

Appendix 6: Survey sample characteristics

Characteristics of Survey Sample		n=
Gender*	**%**	***573***
Male	24	
Female	76	
*one survey respondent identified differently		
Gender of person that you support*	**%**	***567***
Male	47	
Female	53	
*one survey respondent reported that they identified differently		
Age		
Mean age (respondents)	64	*569*
Mean age (respondents caring for spouse)	74	*267*
Mean age (respondents caring for parent)	54	*249*
Mean age (person living with dementia)	81	*571*
Health		
Lives with other health conditions*	60%	
Mean number of additional health conditions*	1.1	
Person living with dementia lives with other health conditions**	77%	
Mean number of additional health conditions**	1.8	
*includes high blood pressure or hypertension, angina/heart attack/congestive heart failure, diabetes/high blood sugar, stroke, chronic lung disease such as chronic bronchitis or emphysema, asthma, arthritis including osteoarthritis or rheumatism, cancer/leukaemia/malignant tumour, visual impairment/ blindness, hearing impairment/deafness, autism/ADHD/dyspraxia/neurodivergent/other		
**includes a physical disability, sight loss, hearing loss, a mental health problem, mobility problems, problems connected to ageing, a learning disability or difficulty, terminal illness, alcohol or drug dependency, or other		
Relationship to person living with dementia: they are my	**%**	***574***
Spouse	43	
Partner	4	
Parent	44	
Brother or sister (including adopted, half and step-siblings)	1.2	
Child	0.3	
Other (included grandparents, other relations, in-laws/partner's parents, step-parents, friends and ex-spouses)	7.5	

Characteristics of Survey Sample		n=
Do you live with the person in the same household?	**%**	***572***
Yes	60	
No, I live elsewhere	27	
I live elsewhere but sometimes or often stay overnight with them or them with me	12	
We live on the same property but in different households (e.g. annex or flat)	1	
If co-resident, does anyone else live with you?	**%**	***377***
No, just the two of us	82	
Yes someone else or other people	18	
How long do you believe your family member's dementia has affected you as a carer?	**%**	***568***
Less than a year	3	
1 – 2 years	22	
3 – 4 years	30	
More than 4 years	44	
Don't know/not sure	1	
How would you describe your financial situation?	**%**	***518***
Living comfortably	37	
Doing all right	36	
Just about getting by	20	
Finding it quite difficult	4	
Finding it very difficult	3	
Wellbeing measures		
SIDECAR quality of life (scale 0 -100, higher is worse)[mean]	56.9	*516*
Lonely	57%	*515*
4+ depressive symptoms	66%	*450*
Moderate or severe anxiety	37%	*498*
Life satisfaction 0 - 10 [mean]	5.33	*510*

The report and related documents are available at:
https://www.opfpru.nihr.ac.uk/our-research/projects/the-impact-of-care-act-easements

This publication is available at:
https://documents.manchester.ac.uk/display.aspx?DocID=64488