

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

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QUESTIONS ANSWERED:

Q1

ANSWER:

Only broad generalisations are possible, since dementia is so diverse. a)Dementia sufferers themselves - perceived loss of autonomy and of familiar "reciprocity" in their relationships, loss of self-esteem, and the fear and anxiety consequent on these phenomena. b)Families and informal carers - unpredictability (especially of behaviour change and perceived risk) corresponding fear of ability to cope, and of altered lifestyle, with loss of reciprocity in relationship, sometimes amounting to a quasi bereavement, lack of confidence in the health and social care systems. c)Society - the cynical exploitation of the spectre of unaffordability - a political ploy unsupported by evidence to divert accountability as well as properly targeted investment in services and research. Informal carers require above all else access to (1) expert, skilled and prompt crisis intervention and advice when the occasion demands, (2) skilled and sensitive assessment, treatment and management of intercurrent health events (including the "general" health services - not solely old-age psychiatry) and (3) predictable and carefully tailored respite programmes linked to periodic reassessment of the individual.

Q2

ANSWER:

1) All forms of restraint, including pharmacological measures. 2) End of life decision making. 3) Financial and other forms of elder abuse. 4) Consent to interventions ranging from surgical and other invasive and/or intensive interventions, to those involving social care or relocation. 5) Disagreement concerning best interests between professionals and relatives, "guardians", or attorneys. 6) Competence and rigour in the assessment of capacity 7) Political and economic "utilitarianism" as a pretext to restrict investment and research.

Q4

ANSWER:

See response to Question 3. The evidence about ethnic groups other than "white British" groups doing better is highly debatable, especially in the UK. Traditional family care" in Southern Asia is often eulogised, when in reality it is widely used as an alibi for the development of quality health services for older people both at home and abroad.

Q3

ANSWER:

Although there may be differences in perception, the realities and needs are essentially the same across ethnic groups. Other than the absolute principle of equity, the issues for dementia care service provision are not primarily ethical, but are matters of cross-cultural knowledge and awareness, communication and sensitivity. A key practical issue is to ensure that access to services is not negatively influenced by reticence on the part of users or inequity or insensitivity on the part of providers.

Q5**ANSWER:**

The recent debate and Guidance around cholinesterase inhibitors has been unhelpful. These agents have exhibited genuine potential for useful modification of symptoms in responders (who are a subset of Alzheimer's disease sufferers). The possibilities for flexibility of use and further evaluation (including the early identification and withdrawal of non-responders) have been inhibited by the premature imposition of the strict economic model. The potential for significant disease modification is however still awaited, and it would be premature to single out any particular laboratory-based line of enquiry. In the meantime, there has been insufficient emphasis on the potential and need for genuine advances in clinical practice and service delivery.

Q6**ANSWER:**

Early diagnosis can only bring benefit provided that the information and subsequent intervention, if any, is handled with sensitivity, skill and expertise. A major argument is the need for sound differential diagnosis to exclude related conditions that may present with reversible cognitive decline. Ethical problems are most commonly raised by cack-handedness in the diagnostic process and the associated relay of information to individuals and their carers.

Q8**ANSWER:**

I think stigma may play quite a substantial part, particularly in the desirable pursuit of early diagnosis. Classic examples particularly involve concealment by spouses. Accurate and firm diagnosis can be problematic, so that in particular an early pursuit of differential diagnosis is important. There is therefore a need to be aware of the role of stigmatisation and to discourage concealment.

Q9**ANSWER:**

In a word, Yes. The urgent need to recognise existing benchmark dementia

services in old age psychiatry and to improve those with deficient technical or governance performance is the way forward for this. Quality services attracting public recognition and confidence would provide the framework within which this process could be taken forward, as has been the case with palliative care. As with so many other aspects of dementia care, the need is to categorise and recognise the best expertise, and facilitate and enable the standard bearers to generate their own campaigning public platform of public information and engagement. Integration of dementia sufferers wherever possible as a recognised part of everyday community living would then be enabled.

Q7

ANSWER:

The prevailing responses include avoidance, uneasy humour and stigmatisation (until it's one's own relative rather than the "group"). Sadly these perceptions pervade politics, health economics, and to a significant degree my own profession (medicine).

Q10

ANSWER:

The idea of person-centred care is fundamental, but should not be promoted as an "alternative" approach or discipline to what is rather disparagingly categorised as "over-medicalisation" or in other contexts "the medical model". The given definition of person-centred care is one the medical profession should legitimately aspire to see represented as a key benchmark for every decent practising clinician. Having said which, one would also wish to see it across the full range of social and health care professionals working together in a multidisciplinary manner, as well as perhaps supporting some particular initiatives (e.g. from the voluntary sector) to deliver it for all dementia sufferers. Any strategy, however, to marginalise the "medical model" in, for example the assessment and management of aggressive behaviour is one we must oppose. Cognitive deficit may characterise other conditions and invariably warrants a diagnostic and review process. Worsening of cognitive deficit in dementia sufferers may also have a genuinely "organic" basis, and it is essential that such possibilities and their treatment are professionally and clinically considered in an expert manner. If "person-centred care" means a dementia sufferer with diabetes exhibiting aggressive behaviour doesn't get their hypoglycaemia, or sepsis, or subdural haematoma, or myocardial infarction diagnosed and treated, (to mention a tiny number of possible differential diagnoses) I'm against it! In the matter of life-threatening illness, where there is doubt, it is in my view essential for the benefit of such doubt to be strongly weighted in the direction of the individual's current experience. Elsewhere lies a slippery slope of patronising proxy interpretation of that individuals supposed wishes, based on past expression, for which we cannot ethically ensure the required safeguards.

Q11

ANSWER:

Entirely incorrect. Personhood is inherent in being human. We judge it to have been lost at our peril, whatever the manifestations of behavioural change or cognitive loss. However hard sometimes (for spouses in particular), we should never entertain the possibility of such a judgement being ratified. The expression of a relationship may change under a range of pressures and emotionally charged situations but its existence cannot and must not. The same applies to any professional relationship.

Q12**ANSWER:**

Such changes can have profoundly damaging effects on relationships. They present an enormous challenge to professional care in terms of support for others involved in that relationship. Pragmatic strategies (sometimes changes in previously agreed strategies) are essential to ease the burden for those involved, in such a way that the illness of dementia is able to be observed, categorised and recognised for what it is, without imposing impossible demands and pressures, but also steering carers away from disproportionate reactions, ranging from rejection to profound guilt. There is a major but key emphasis in such situations on the accountability of the services for carers.

Q15**ANSWER:**

Dementia may be associated with a long prognosis for life. As with any other condition with a highly uncertain prognosis for life (such as "arteriopathy", for example) the diagnosis per se (as distinct from its progression and/or manifestations) should not be a prominent part of the decision making process. A complete judgement should be reached taking all aspects into consideration, the most central of which must be the capacity to benefit from any intervention.

Q13**ANSWER:**

See my response to Q10. Neither the view expressed in option 1 nor that in option 2 in the document is entirely satisfactory. However the bias should be towards option 2. We cannot make reliable judgements about the present based on past expressions alone. Even if they were wholly rational and considered at the time, they will have been based on assumed predictions of the future that cannot necessarily have covered every possible eventuality. Therefore consensus on a balance of both needs to be assiduously sought together by professionals and carers.

Q14

ANSWER:

However difficult, there must not be a formulaic approach to this. An iterative process is necessary, but the ethical "safety net" of "respect the person's expressed wishes unless they are demonstrably harmful" is appropriate. Getting the definition of "demonstrably harmful" right in any particular case is a difficult, but not necessarily impossible, judgement. It is capable of being well (or badly) made together by professionals and carers, and still allows for "best interest" to be correctly identified.

Q16**ANSWER:**

In many cases mature and thoughtful attorneys who genuinely have the individual's best interests at heart can be immensely helpful in reaching consensus with professionals on the way forward. Others (thankfully a minority) pursue a campaigning and disproportionate agenda that makes it impossible for professionals to adhere to a balanced ethical framework. On the whole, the current procedures for resolving disputes represent a satisfactory framework, except that they may be too slow.

Q17**ANSWER:**

Option 3 of the three positions is the best and most balanced. The interpretation of a previous advance directive in accordance with ethical standards will invariably involve elements of judgement about the precise nature of the immediate circumstances and of the possibilities that actually exist at the time. Individuals should feel free to draw up advance directives if they genuinely believe this will be of help to those (both professional and non-professional) who will be caring for them in the future. They can and should never, however, take the place of the immediate ethical duty of care at the time, and their use for "defensive" purposes should therefore not be encouraged.

Q18**ANSWER:**

In my experience overall the impact of the legislation has largely balanced out at neutral. In some circumstances it has fostered division between professionals and relatives, while in others it has genuinely assisted the achievement of consensus. Legislation in dementia care is a blunt instrument that is sometimes useful. Its place should not be to provide a substitute for progressive professional quality and robust governance.

Q19**ANSWER:**

Lying is almost invariably counterproductive. Skill in sharing "truth" in a manner

which is helpful to dementia sufferers is one of the challenges of the field. "Achievers" in the field often do it brilliantly, and their skill should be better recognised.

Q20

ANSWER:

The prevailing cultural bias is towards being too restrictive. The recent German court judgements have undoubted merit, particularly since physical restraints have historically been indicators of inadequate numbers, skill mix and practice standards of so-called professional staff and services. The alternatives of course presents greater challenges - but "beacon" examples have clearly demonstrated that they are achievable.

Q21

ANSWER:

Every effort should be made to keep their use to a minimum, and there are of course "degrees" of restraint, some amounting to little more than improving environmental safety with minimal impact on freedom. The alternatives, however, require adequate investment, training and recruitment of achievers, together with dissemination of best practice, research and innovation - but targets for minimal restraint (including pharmacological restraint) have been set by benchmark units. The objective is the right one and the current care home regulations are essentially correct. The difficulty (as with a substantial range of putative "ethical" issues in dementia care) is in fostering and resourcing the levels of skill required for their implementation.

Q22

ANSWER:

Absolutely. Specialist skills require strategic expansion and clarity on ethical issues will be part of such training programmes. The career structures must be resourced, the skill mix raised and the field de-stigmatised. But truly ethical issues must be distinguished from those that purely reflect substandard practice.

Q23

ANSWER:

Technologies are no substitute for expertise. In the right hands at the right time they have a place. In such a context the ethical concerns become far less significant. Tagging and smart homes are not unethical in themselves and may have some place as part of skilled, individualised care programmes. Used inappropriately as substitutes and in the wrong hands, they are almost uniformly ineffective (as well as unethical). Hence the poor take-up.

Q24

ANSWER:

The principles of state responsibility are no different from those accepted for any other form of health and social care need. There is no ethical distinction. There is sadly substantial wastage in the system due to inadequate or inconsistent expertise in the assessment of need and to bureaucratisation of service delivery. This has had a profoundly discouraging impact on the state's major "natural" resource, the continued engagement of willing carers. "Unaffordability" then becomes a pretext for state abnegation of duty.

Q25**ANSWER:**

See question 24. A properly resourced and capable service that is supportive to carers strongly tends to reconcile these conflicting interests.

Q27**ANSWER:**

See Q 26. The reconciliation of such interests should be part of a continuing programme of standard specialist multidisciplinary dementia care practice. The setting of benchmarks then enables the principle of equity to be applied in considering the interests of one set of carers or households in comparison with those of another.

Q26**ANSWER:**

The health care system in separating off the administrative and budgetary responsibility for long term care to the means-tested social sector has failed carers. Carers need to be supported by regular specialist advice that they trust, the guarantee of immediate emergency response in a crisis, individualised respite services, and a genuine experience of "partnership" with NHS specialist services, which themselves should enjoy a genuine working partnership with social care. This requires the amalgamation of budgets to deliver a single comprehensive dementia programme. Under these circumstances the so-called conflicts of interest become less, and it also becomes more feasible to promote equitability as a basis for resolving conflicts where they do occur. The actual configuration of services is thus fundamental to the contribution of health and social care professionals.

Q28**ANSWER:**

Best multidisciplinary practice (a substantial part of which also entails open engagement with carers as well as sharing information amongst professionals) results (by implication) in a reduced emphasis on confidentiality. If it's done

properly, consensus on information flow is generally achieved, almost always with the agreement of the individual concerned. I see it as a challenge to best practice, rather than in the real world of care delivery an inherently ethical concern

Q29

ANSWER:

The parallel objectives of the pursuit of disease-modifying agents on the one hand and evaluation of services as part of health technology on the other need to receive comparable priority (along with a range of objectives somewhere between the two). The figures on research funding speak themselves. Practice development and service delivery are proceeding against the background of a still woefully inadequate evidence base.

Q30

ANSWER:

I see no reason in principle why proxy consent is unacceptable for studies involving those with advanced dementia, but there are very obvious limitations on what might be asked of them, beyond non-invasive observational measures. However, such studies may be vital in, for example, defining optimal strategies for nursing care, symptom management and environmental support, and require very careful ethical scrutiny. As already stated, the need for evidence is stark. In terms of the need and the value of evidence we should be guided largely by leading clinical academics in the field of old-age psychiatry (of which I am not one!).

Q31

ANSWER:

I think the current ethical regulatory framework is broadly satisfactory in principle, but the sheer scale of bureaucracy has become massively daunting and a major disincentive to putative researchers, especially in the clinical and health service research arenas. Some attempt should be made to ease the situation.

Q32

ANSWER:

As may be apparent from some response above, I have a slight preoccupation that there is a correlation between the prevalence of problems that present as ethical and the scale of substandard, de-skilled or inadequately resourced professional practice and service provision. Where models of good practice are in place the frequency of ethical dilemmas (e.g. around restraint), although they may still exist, is less. In my view, the best benchmark services in Old-Age Psychiatry are weakening the case for further legislation in dementia and

incapacity and are instead flagging up the matter of how expertise should be promoted and resources best identified and deployed. Perhaps this last is the most pressing strategic concern, albeit one with ethical overtones. I commend the Council for undertaking this review, but strongly urge that the need to achieve more uniform implementation of expert, skilled, unified, multidisciplinary services for dementia be identified as a key component of the way through many of the putative ethical problems so readily flagged up by those not genuinely in search of solutions.