

26 August 2010

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Dear Mr Chapman

Improving Dementia Services in Northern Ireland – A Regional Strategy

We are writing in response to your consultation on the draft dementia services strategy for Northern Ireland. Our comments, set out in Annex A, are drawn from the Nuffield Council on Bioethics report *Dementia: ethical issues* published in October 2009. The report is available to download at www.nuffieldbioethics.org/dementia. A copy will also be posted to you, along with a hard copy of this response.

Please do not hesitate to contact me if you would like further information or assistance.

Yours sincerely



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Annex A

Comments from the Nuffield Council on Bioethics on 'Improving Dementia Services in Northern Ireland – A Regional Strategy'

Background

- 1 The Nuffield Council on Bioethics published a report *Dementia: ethical issues* in October 2009. The report was prepared by a Working Party established in 2007 to examine the ethical issues raised by dementia. The Working Party was chaired by Professor Tony Hope, Oxford University, and included members with expertise in medicine, nursing, neuroscience, law, sociology and philosophy, and members representing people with dementia and carers. To inform its deliberations, the Working Party held a public consultation and spoke to people with direct experience of living with dementia and those working in the field.

General comments

- 2 We very much welcome both the concept of a dementia strategy for Northern Ireland, and the content in the current draft. Many of the recommendations in the draft strategy concur with the recommendations of the Nuffield report. Specific comments on the content are outlined below.

Values and principles for dementia services

- 3 We applaud the authors of the strategy for setting out a set of values and principles to underpin the future development of services (ie dignity and respect; autonomy; justice and equity; safe, effective, person-centred care; care for carers; and skills for staff). In its report, the Council set out an ethical framework to help those who face ethical problems in the day-to-day care of someone with dementia, and there is much overlap. The strategy authors might also consider considering the following additional values and principles (see Box 2.1 on page 21 of Nuffield report):
 - **Component 4: The importance of promoting the interests both of the person with dementia and of those who care for them:** People with dementia have interests, both in their autonomy and their well-being. Promoting autonomy involves enabling and fostering relationships that are important to the person, and supporting them in maintaining their sense of self and expressing their values. Autonomy is not simply to be equated with the ability to make rational decisions. A person's well-being includes both their moment-to-moment experiences of contentment or pleasure, and more objective factors such as their level

of cognitive functioning. The separate interests of carers must be recognised and promoted.

- **Component 5: The requirement to act in accordance with solidarity:** The need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and in society as a whole.
 - **Component 6: Recognising personhood, identity and value:** The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions.
- 4 We would also like to highlight that *how* things are done, so that people with dementia feel valued individuals, will often be far more important than the particular structure or format of services (paragraph 3.5). Secondly, we highlight the enormous importance of families and friends in the care of many people with dementia. It is our view that an attitude of working with families and other carers, supporting them in their own care of the person with dementia, is most conducive to the interests of the person with dementia and best recognises the centrality of relationships with family and friends for many people with dementia. We suggest that the appropriate attitude of professionals and care workers towards families should be that of partners in care, reflecting the solidarity being shown within the family (paragraph 3.12).

Raising awareness of dementia

- 5 We welcome the strategy's aim to increase awareness of dementia among the general public, those working in services which interact with the public, and those working in health and social care. The Nuffield Council concluded that for dementia to be truly normalised, it needs to become an accepted, visible part of our society, in the same way that physical disability is increasingly recognised as part of the norm.
- 6 You discuss the need to work with people who deliver public services to people with dementia to tackle stigma. People with dementia also need to feel comfortable going to a club or out to lunch, participating in the life of a church, or taking part in voluntary work, just as they did earlier in their lives. "Service providers" such as shops, leisure services and restaurants have a legal duty under the Disability Discrimination Act 1995 to make "reasonable adjustments" to enable people with dementia to access those services. However, they will often not realise this, and even if they do, they are unlikely to have sufficient knowledge of dementia to make appropriate adjustments.

Supporting people with dementia

- 7 We welcome the proposal to provide advice and support at the time of diagnosis of dementia, and a contact point should he or she wish to ask questions or seek further help later.
- 8 Going one step further, the Nuffield Council suggests that an important element in providing support will be the identification of a single individual to liaise with the person with dementia and their family, and with whom a trusting relationship can develop. We welcome the proposal in the English dementia strategy to pilot possible models of 'dementia care advisers', whose role would be to help people diagnosed with dementia access appropriate services and support. We suggest that there is a strong ethical justification for such a role to be introduced throughout the UK as soon as possible.

End of life care

- 9 End of life care for people with dementia is a matter of particular concern, with evidence to suggest that people with dementia are less likely to receive palliative medication, have attention paid to their spiritual needs, or be referred to palliative care specialists than people who do not have dementia.
- 10 We welcome the recommendation that Trusts should develop palliative and end of life services for people with dementia within the framework of the palliative and end of life care strategy. A key factor will be the development of models of end of life care which are appropriate to dementia. We also strongly agree with the National Council for Palliative Care that close working locally between those responsible for dementia care and those responsible for end of life care is absolutely crucial.

Making decisions

- 11 The Council makes a number of recommendations with regard to the mental capacity legislation covering England, Wales and Scotland. This may be relevant to the development of the new legislation for Northern Ireland:
 - In our view, most people do not make 'autonomous' decisions in isolation: rather they come to decisions supported by those close to them and in the light of those relationships. Joint decision making with trusted family or friends is one example of how our broader approach to autonomy can be realised in practice, and is potentially valuable, both in meeting the legal requirement to take all practicable steps to support a person in making their own decision and in supporting the person in 'borderline' cases where their capacity is uncertain. We recommend the

Codes of Practice made under the Mental Capacity Act and the Adults with Incapacity (Scotland) Act should be amended to emphasise the importance of good communication and supportive relationships with families, so that joint decision making is encouraged wherever appropriate. (Paragraph 5.23)

- We recommend that the mental capacity Codes of Practice should be amended to provide additional guidance on how past and present wishes and preferences should be taken into account where these appear to conflict. This guidance should emphasise that neither past nor present can automatically take precedence, but that the relative strength of the person's wishes, the degree of importance of the decision, and the amount of distress being caused should all be important factors to consider. (Paragraph 5.32)
- We are concerned about the current lack of consensus as to whether an advance refusal made under the Mental Capacity Act could be invalidated by inconsistent behaviour after loss of capacity to make the decision in question. Such a lack of clarity adds to the concerns on the part both of those who wish to write binding refusals and of health professionals who have to act upon them. We recommend that the Department of Health should act quickly to provide additional guidance in the Code of Practice on whether advance refusals may be invalidated by inconsistent behaviour *after* the person has lost legal capacity to make the decision in question. (Paragraph 5.42)
- Where individuals wish to make decisions about their future care, we strongly support the notion that this is best achieved within the broader context of advance care planning (paragraph 5.48).
- We believe that, in supporting and facilitating decision making on behalf of people who are inherently vulnerable as a result of their declining capacity, welfare powers of attorney represent a 'social good' and that, as such, they should, in principle, be available free of charge for everyone. At the very least, a funding mechanism should be found in order to ensure that when a person is first diagnosed with dementia they are actively supported in nominating a welfare attorney if they so wish (paragraph 5.56).
- We recommend that the Codes of Practice both for England/Wales and for Scotland should explicitly address the question of when it is appropriate for professionals to seek to override the decision of a nominated welfare attorney by approaching the Court of Protection, the Mental Welfare Commission or the Court of Session. Both professionals and welfare attorneys would then be clear as to their respective positions. Our view is that significant weight should be placed on the fact that the person on whose behalf the decision is being taken has

actively chosen, in the past, to trust the welfare attorney to act on their behalf. This would suggest that others should seek to intervene only if they have grave concerns about the welfare of the incapacitated person, and not simply because they themselves take a different view of best interests. (Paragraph 5.63)

- We emphasise in our ethical framework that the difficult problems which often arise in dementia do not lend themselves to formulaic answers, and that indeed there will often be no straightforward 'right' or 'best' answer. The approach to 'best interests' and 'benefit' set out in the mental capacity legislation and Codes of Practice is very helpful, in that it encourages a flexible approach to decision making that looks at the individuals and circumstances involved in each particular case. We reiterate here the fundamental importance of approaching such decisions not only with flexibility, but with compassion, founded on respect for the value of the person with dementia (paragraph 5.66).
- The Working Party strongly supports the current legal position that when a person lacks capacity, their confidential information should only be disclosed to others where it is in the best interests of the person to do so. We believe, however, that the current guidance in the Mental Capacity Act Code of Practice on *when* it will be in a person's best interests to share information is too restrictive. Professionals should be made aware of the legitimate reasons why carers may ask for medical or other confidential information, and ordinarily start from the assumption that if a carer is involved in making a decision on behalf of the person with dementia, then they will need the same level of information as any other member of the care team. In short, carers should be provided with any information that it is necessary for them to know in order to carry out their caring role (paragraph 7.26).

Research

12 We welcome the strategy's aims to grow the local research effort on dementia, by promoting access to, and effective use of, expertise and funding. We highlight a number of areas where further research is particularly important:

- health services research into how people with dementia and their carers can best be supported to live well, how mainstream services can best be adapted to their needs, and how good practice can more readily be implemented;
- more meaningful outcome measures for assessing the effect of particular forms of treatment or service;
- research into how best to improve the provision of support for ethical decision making;
- all forms of research for the non-Alzheimer's dementias; and

- research into preventative strategies.

We particularly highlight the importance of social research on:

- how people live with dementia,
- the nature of their experience and the quality of their lives;
- how stigma can best be challenged; and
- how those working in health and social care can best be supported in providing care which genuinely respects the personhood of everyone with dementia.

Additional points

13 The Council makes a number of additional points that are not currently considered in the strategy.

- More guidance for carers is needed on when restraint might count as 'proportionate'. Carers need more support to help minimise the need for restraint at home. (Paragraph 6.38)
- Protecting people from harm is important, but minimising the risk of harm to a person with dementia may reduce their quality of life. 'Risk assessments' should be replaced by 'risk-benefit assessments' that take into account the well-being of the person with dementia. (Paragraph 6.17)