Ethical issues in dementia care – summary

A total of 34 people responded. Some had collated responses from others. When describing the issues experienced, one carer used the term “Someone” to characterise the person cared for.

1. Decision making and capacity (choice and competency)
   a. Autonomy v. protection. What to wear, what to eat
   b. Consenting to or declining assessment
   c. Decisions about moving into a care facility
   d. End of life decisions, medical treatments such as resuscitation, nutrition and hydration (artificial feeding) at end of life
   e. Financial decisions, eg. understanding how long term care is financed
   f. How to assess capacity
   g. How well were risks/benefits/consequences/alternatives really understood? What do we do when people make “unwise” decisions?
   h. How to deal with fluctuations in capacity, and partial capacity.
   i. How to include people with dementia in processes such as case conferences. How can communication be supported?
   j. Discharge planning (from hospital). What if next of kin are making decisions which are not in the best interests of the patient (a lot of the discharge plans have significant financial implications for the family), or if the partner has little insight to the degree of dementia, or has dementia themselves?
   k. What if the rest home is quietly assuming responsibility for welfare decisions while no EPOA has been appointed? At what point does the family court step in?
   l. What can we say regarding conjugal rights and consent?
   m. What should rest home staff do if two residents start a relationship and one or both of them still have partners in the community?

2. Informed consent for research
   a. If too stringently adhered to, can lead to too little research being done. How can we manage this so that people with dementia can participate in research?

3. Truth v. peace; trust and deception
   a. Eventually family members end up not quite telling the truth, to keep the peace, rather than keep on arguing
   b. How do I act when others discuss my Someone as if they cannot hear or comprehend? Such others could be friends or professionals. Addressing this with them carries the risk of offending them and hurting the relationship or reducing the support available.
   c. What do I do when my Someone lets me know, or I observe, that bad practice is occurring? If we challenge the bad practice, I fear repercussion.
   d. I must weigh my responsibilities against my Someone’s express wishes (eg My Someone urged me not to do or say anything for fear of “causing trouble”)
e. Do I tell my Someone I have disregarded their wishes? Or not, so as not to exacerbate their anxieties? I risk losing their trust if they learn I took action; even if I tell them, they may not confide in me again.

4. Patient confidentiality /autonomy v. safety/sharing crucial information with family carers
   a. How much to share with family carers if the person with dementia doesn’t want you to?
   b. Can family access help/ discuss their Someone with GP etc before EPOA has been activated?

5. Legal issues
   a. Understanding Enduring Power of Attorney, Welfare Guardianship, and Personal Orders
   b. What if wishes have not been documented although they are known by family?
   c. Is the EPOA acting in the best interests of the person with dementia? Or even if they are, are they going about it in a respectful way?
   d. What if the EPOA’s decisions conflict with those of other family members?
   e. Has the ‘right’ person been appointed? E.g. now living overseas but nearby family powerless
   f. When to activate/deactivate the EPOA?

6. Service provision
   a. When to intervene in the community?
   b. What if neglect/squalor/alcohol abuse predated dementia?
   c. Expectations of referrers and families when the person refuses professional help with personal cares/housework
   d. When to do a cognitive assessment. Timing of diagnosis
   e. Family resistance to cognitive assessment or services
   f. Disagreement among family members
   g. How to promote access to services
   h. Delay (caused by any other issues) and risk before services can be accessed. Eg several weeks before continence consult: risk of skin issues, bladder infections, constipation, carer burden
   i. Access to palliative care often denied because dementia is not always recognised as a life limiting illness
   j. Balancing invasive treatments with quality of life. Failure to recognise dementia as a life limiting illness may mean that treatments are started or continued unnecessarily, eg intravenous fluids, admission to acute hospital
   k. How does the person with dementia communicate? Especially regarding pain and suffering, so that this can be adequately assessed and managed.
   l. Cultural differences
   m. Is it right that people of means have their residential care or other services paid for by the tax payer, leaving fewer resources for others who need them?
7. Availability of services
   a. Young fit people being placed in the same environment as frail older people with limited mobility
   b. Non-English speaking people placed in secure dementia unit because of language needs when they really required only rest home care
   c. Training/qualifications of support workers to provide specialist support
   d. Access to respite care and day care
   e. Lack of beds may result in use of chemical restraints
   f. Lack of support may result in carer stress and elder abuse

8. Balancing the needs of caregivers with those of the person with dementia
   a. Carers have to balance their own needs with their loyalty to the person with dementia. Sense of guilt when putting self first. “I promised I wouldn’t put her in a rest home.”
   b. Using day programmes or respite care when the person doesn’t want to go but the caregiver is in desperate need of a break.
   c. When to visit? They may get upset when I visit, and want to come home. If I don’t visit, they may fear I have abandoned them.
   d. When to consider moving to residential care.
   e. Impact of moving into care. Eg. Loss of the superannuation payment. Perceived cost of care. For those living in a HNZ property, if it is the person on the lease who will be moving out, the others have to vacate the property
   f. Carers may have their own (health) issues and not necessarily report difficulties or seek help
   g. Particularly for Maori, Pacific and Asian families: balancing whanau interests with individual autonomy
   h. The use of medications, and, once prescribed, a review to see if they can be withdrawn. My Someone has a fixed but mistaken idea that their medication is harming them. Should I administer by subterfuge because it relieves their symptoms and means I can continue caring?
   i. Managing behaviours that challenge. Eg. use of sedation to enable them to be managed at home (or in a the facility they live in); locking in bedroom at night to prevent incontinence elsewhere in the house

9. Elder abuse
   a. Loving family carers may experience distrust from professionals
   b. Safety v. risk/abuse/legal authority. How do we protect people with dementia without taking away their rights? Cold callers, internet scammers, handyman imposters, website romances…
   c. Some abusive situations may be the result of carer stress or ignorance
   d. Discrimination
   e. Reporting of elder abuse
10. Balancing risk with freedom and enjoyment; safety with autonomy/ preference.
   a. I try to allow my Someone to take some risks in life, but other people don’t agree that the risk levels I permit are reasonable and may intervene in ways that are undermining. Will you get into trouble if you try to maintain the person’s independence?
   b. Physical as well as emotional safety
   c. Is it safe to leave the person with dementia alone?
   d. When and how to start limiting someone’s freedom to keep them safe.
   e. When do you take over chores that they can no longer do safely e.g. taking medication, cooking, giving up control of finances?
   f. Wish to stay in/ return to own home when this would be unsafe.
   g. Driving: when do you ‘dob in’ your family member, GP reluctant to tackle this. How much may I tell others about this and other difficulties arising because of their dementia, when my Someone does not do so nor wishes such things to be revealed?

Thoughts on Providing Guidance:

It is not possible to construct a prescriptive “users’ manual” for every situation a carer may find themselves in. Some speak of “situation ethics” and that may not be a bad way to approach these dilemmas which are very real, frequently recurring, often complex and seldom easily solved.

There will also be a personal dimension to this kind of problem. Some carers, including me, believe it is always wrong to lie, since maintaining trust is paramount. Others may feel that a “lie of omission” is allowable in some circumstances.

If the carer can always try to put themselves in their Someone’s shoes, this may help. Or they may adopt a rule linked to their own sense of values, such as:

- I will strive to give my Someone as much freedom to choose as I possibly can. (“Self determination” as some professionals call it)
- If I do have to take action to minimise harm or distress, to do so in the least restrictive or intrusive way possible.

Often there are no obvious answers and talking the situation out with others may help to resolve a dilemma.

Notes on communication

When wanting a decision from a person with dementia, they should be approached when they are at their best e.g. when they are relaxed, not suffering from other health problems that might make cognition worse (e.g. UTI) and at a time of day when they function best. And the necessary information needs to be provided in an understandable way.

Do we do enough to support the communication ability of a person with dementia? For example, adding written language and/or pictures with captions to verbal explanations to aid comprehension; providing opportunities for indicating choices non-verbally, for example, by pointing.
References that were suggested

Dyall L (2013) Dementia: Continuation of Health and Ethnic Inequalities Submitted to NZMJ


