King's Fund

When We Are Very Old

Report of a King's Fund Staff Event held on 13 April 1999

1 Introduction

Following a seminar for front-line health, housing and social care professionals, King's Fund staff were invited to take part in an afternoon event on 13 April 1999 to consider current care arrangements and provision for older people; and to discuss their thoughts on what they would want should they need treatment, care and support in their own old age.

A large number of staff from a range of departments, and with a variety of roles and responsibilities, took part. The views of some staff who were not able to attend on the day also helped to inform this report. This report is a summary of the discussions which arose from three main activities during the afternoon:

- Working in pairs, each person told a favourite story about an older person; each listener recorded two words or phrases which stood out from the story. These words and phrases are listed in the appendix;
- Small groups compiled lists of things to be proudest of, and sorriest about, in the current treatment, care and support of older people; then each person (anonymously) allocated 'votes' to the items on all the lists;
- Four groups separately considered the key things they would - and would not - want if treatment, care and support were needed in their own old age, if they were:
    1. Living alone
    2. Living as a couple, with you as a carer
    3. Living as a couple, with you being cared-for
    4. Living with family.

Overall, those attending were proudest of:

- Older people having access and control
- The rise in 'grey power'
- Leisure and education opportunities for older people

and sorriest about:

- Older people being seen as a burden, and a drain on the economy
- Poverty in old age, including the inadequate level of pensions and benefits
- A lack of respect for older people

For the future, having sufficient pension income would be a key to remaining independent, keeping a sense of dignity, and being able to exercise choice. There were strong expectations that older people would be positively included, rather than marginalised, in a future world and society. Being regarded as an individual, and being enabled to live in the way chosen by an individual were also extremely important: as was the right to decide about when to die.

Overall, a range of diverse issues emerged were discussed. These broadly divided into separate themes of services, staffing and quality of life.

2 Services

2.1 Access through assessments

There were particular concerns about older people having to wait for services or equipment, especially when these were needed straight away. This included waiting for assessments to be carried out, as the first stage in obtaining support. If older people had to wait, their conditions and circumstances often deteriorated. This led to more support being needed. One example was of someone whose condition deteriorated to such an extent whilst waiting for a stairlift to be provided at home, that he had to move instead into residential care.

2.2 Alternatives to hospital and care homes

Most concerns were about what happened whilst older people were in hospital and care homes. For example, a lack of staff meant poorer quality inpatient care; whilst those in care homes were not always helped to remain as independent as possible. In addition, some older people feared going into hospital because of a belief that they would never be well enough to leave. Policies which promoted rehabilitation services were particularly welcome, including the focus within the King's Fund on rehabilitation for older people. Sheltered housing schemes were positive alternatives to care homes.

For their own old age, those attending wanted adapted accommodation which met their needs, together with a choice of different types of accommodation in a variety of locations.

2.3 Primary care

There were concerns about a range of primary care services, mostly focusing on insufficient provision. This included insufficient chiropody and incontinence services, and the erosion of the health visitor role in care of older people. Primary led health care was felt to be patchy. There were some concerns about over-

medication, although others felt positive about the reduction in the use of tranquillisers amongst older people. District nursing services and physiotherapy were mentioned as good services for older people; and the over-75s annual health check was welcome because older people liked this.

For their own old age, participants wanted health care to be provided when it was needed.

2.4 Rules and regulations

There was a great deal of concern about what was described as the 'lottery of care'. Because there was no consistency in the treatment, care and support older people received, there were inequalities. There were a number of concerns that the overall system was very complicated for older people to understand and use, including the benefits system. There were too many forms which had to be completed in order to receive services or financial support, but often there was no-one to help fill these in. In addition, there was particular disquiet that people who had been frugal during their lifetimes were penalised financially if they needed care in old age.

Government policies such as the Better Government for Older People initiative were good; and the Royal Commission's report on funding long-term care for the elderly was also welcomed. Cold weather payments, and the re-introduction of free eyesight tests for those aged 60 and over were positive; and there was a view that there were good health care infrastructures in the UK.

For the future, any systems for treatment, care and support should be sufficiently funded, and flexible enough to meet individual needs.

2.5 Support at home

Key concerns included the lack of someone to check on an older person, especially if an older person lived alone; and the isolating effects of technology

used to check on individuals, such as community alarms. However, some regarded the development of community alarms as positive. Older people also needed help with decorating and gardening, but these were rarely available. Home care services could help older people to stay at home and retain their independence. Day care services, particularly those developed to meet the needs of ethnic elders, were welcome.

There was a need to develop more imaginative respite care for the future, designed to meet the individual wishes and needs of the older person and their family.

2.6 Support in emergencies and 'out of hours' services

There were a number of concerns about the lack of services which could be provided quickly in response to an emergency or crisis. In addition, a lack of 'out of hours' services meant older people might not receive care in the evenings or at night, even though this might be when it was needed.

3 Staffing

3.1 Specialisation, integration and co-ordination

Gaps in service provision caused some concern; as did a lack of advice about how to get better services. Sometimes professionals did not know about any other help their organisation offered, let alone what a different organisation might or might not be able to do. However, where team approaches to care existed, older people benefited. Some specialisation, particularly around palliative care, was positive; but there were concerns about the lack of continuity in staff who provided care, particularly intimate, personal care, such as bathing. Where intimate care was being provided, it was important that this only involved one worker wherever possible, rather than a succession of different staff.

In the future, 'one-stop shops' offering a single point of contact for advice and information would be needed, including links with voluntary groups. Treatment, care and support should be provided when it was convenient to the patient/user, and any services should be reliable. A key worker would be needed to co-ordinate all treatment, care and support.

3.2 Professional attitudes, and the 'culture of care'

A lack of respect for older people amongst professionals was one of the key themes which emerged during the event. Professionals might call older people by their first names without the older person agreeing to this. There were some patronising or condescending attitudes of 'we know what's best for you'. Geriatric care was often given a low status, and this particularly affected the attitudes of nursing home staff, and contributed to poor quality in some residential settings. This lack of respect meant that older people could face rationing of services and treatment because of their age; and gave rise to a much greater emphasis on institutionalised care for older people, compared with a more community-based approach for younger adults with long-term care needs. Malnutrition in hospitals was also a particular problem. In contrast, some

professionals were kind, and this personal quality meant older people received a better standard of treatment, care and support. In addition, and where hospitals were not rationing health care, the use of technology meant that older people received innovative and good quality treatment.

In the future, professionals would need to be honest about what was, and was not available in terms of treatment, care and support.

4 Quality of life

4.1 Dignity

Helping older people to maintain their dignity could be achieved through valuing older people's skills and experiences. Too often, however, older people faced a loss of dignity because their quality of life was adversely affected by having to wait for services and equipment; through being expected to behave like a stereotype of old age, rather than being regarded as an individual; and dying alone. There were particular concerns about the impact of poverty on older people's dignity, especially because of what many regarded as the derisory amounts of state retirement pension, and other state benefits and allowances, payable after a lifetime's work and contributions; and the psychological impact of means-testing on older people because of its stigma of 'charity'.

Having sufficient retirement income in the future was one of the main ways in which dignity could be maintained and enhanced; as was being regarded as an individual.

4.2 Support through bereavement and other losses

Old age was often associated with bereavement and other losses, such as losing independence, and difficulties in accepting that the world had changed. The need for care often brought with it a loss of personal possessions and of pets, because older people could not always take everything with them if they needed care in residential settings. Residential care and stays in hospital could also mean a loss of privacy. Older people were often scared that they would lose their house and possessions, because increased care needs meant they would have to move into means-tested residential care.

Loss of pets as a result of having to move in order for care needs to be met was particularly identified as a concern for the future.

4.3 Choice and autonomy

Insufficient income and savings reduced older people's choices, because they were not able to buy services privately. Information about the help and support which might be available was sometimes poor, resulting in older people not knowing that there was any choice. However, the rise in 'grey power' meant more older people were taking charge of their lives, and were beginning to get very involved in service planning and delivery. There was also greater menu choice in hospital, residential and day care settings, especially for older people from ethnic minority groups.

For the future, a large number of participants raised the issue of having the right to decide when they would die, albeit with some tight safeguards. The right to appropriate sexual expression was also important, together with choosing how and where to live, and with whom. In addition, feeling safe and secure at home and in the wider environment would be essential if they were to feel in control of their own lives.

4.4 Social isolation

If pre-retirement planning was put into practice early in retirement, older people could develop and maintain contacts and networks. If this had not happened, older people who lived alone were particularly vulnerable to feeling isolated and lonely, especially where there was a lack of neighbourliness. Holidays aimed at older people, such as those offered by Saga, were useful in helping to combat isolation and enabling those without a partner or spouse to feel they could go away for a break. Leisure and education opportunities were particularly positive, especially the University of the Third Age. Taking part in activities such as playing Bridge could give a structure to an older person's day or week; and because these activities were often popular amongst all age groups, there were increased opportunities to meet younger adults and for new friendships to grow and develop. Pubs and restaurants which offered cheaper food or drinks for older

people meant those on low incomes might be able to afford to go out. Opportunities for older people to become volunteers should be encouraged.

Having a network of friends and family would be particularly important in the future, whether living alone, with a partner/spouse or with other relatives. There needed to be more events for older people, rather than entertainment being concentrated on those under the age of 25. Having a telephone and access to the Internet would help mitigate any feelings of isolation; services should help older people to remain in contact with friends.

4.5 Participation in community life

It was hard for older people to take part in community life without suitable and accessible transport, particularly public transport. Free bus passes, reduced taxi fares, and 'hop-on/hop-off' buses were good examples of services which enabled older people to travel to the shops, or to visit friends and relatives. Community schemes which involved younger and older people, such as community gardens, were a good way for people to get to know each other and for a sense of community to develop. However, the closure of community facilities, such as libraries and Post Offices, could leave older people facing difficult or impossible journeys. Ordinary services needed to be better geared towards the needs of an ageing population, including greater provision of large print books in public libraries.

In the future, there must be good access to a range of local public facilities such as libraries and sports centres. Access to transport would be crucial, as would locally accessible shops and entertainment. Being encouraged to find a useful role to play in the community would also be important.

4.6 Family involvement

Families often found that they were effectively left to provide care because of gaps in services, and there was often not much support when they were facing

difficult decisions about care for an older relative. Amongst some ethnic groups, there had been a loss of family care.

For the future, there were a number of concerns about not wanting to be a burden to the family; not wanting their family to be embarrassed, nor to feel obliged to be involved. Assumptions should not be made that their families or partners/spouses would do everything, nor that this type of care is what they would want. However, all support mechanisms would need to help them maintain regular contact with relatives.

5 Conclusion

A wide range of concerns were discussed about the current provision of treatment, care and support for older people as well as the improvements which needed to be made for the future.

There was a need to enhance the general view of older people, moving away from a concept of older people being a burden, to recognising the value of their skills and experiences, and encouraging them to draw on these in contributions to the community. As a significant section of the adult population, and as major users of health, housing and social care services, older people should not be invisible: the apparent rise in 'grey power' suggests they may be anything but for the future.

Appendix 1

Working in pairs, each person told the other a favourite story about an older person they knew or know. Each listener then recorded those words, quotations or sentences which had stood out from the other's story. These are set out here as they were recorded; there is no significance to the order in which they appear below.

- "Well if you don't know what my insulin should be, sure as hell I don't!"
- He was jogging with a drip on the end of his nose
- She'd been having a conversation with a BT recorded message
- "Was it you or your brother who was killed in the war?"
- Not being treated like a human being in the new home
- Grateful for help given
- Took to his bed
- Difficult to get on with
- Once the chiropodist had left, she was off down the road
- Amazing, unexpected experiences
- Always complaining
- Battling on
- Lost love
- The basics of relationships are still the same
- Always telling anecdotes and memories of 40 years ago
- Logic
- Childlike
- "In my day…."
- Resourceful
- Worried about her
- Positive influence on others
- "Do you want to see my mastectomy scar?"
- Shameless
- She was very wise

- Witch
- "So what's wrong with peas then?"
- Checking the stock market
- Depressed
- Distressing life events
- Dementia
- Feisty
- Ability to put up with things
- Spy catching during World War Two
- Assertiveness
- Independent
- Kind
- Humour
- Confusion
- Old fashioned
- Maintaining social networks
- Deafness
- Always economical – "Will I get the use out of it?"
- Frightened of staff in the home
- "He just needs to sow his seed"
- Knickers on her head
- Stories were lies
- Youthful outlook
- Getting into a care home and losing touch with reality
- Frail yet fiercely guards independence
- "She's still got it all up there"
- Fabrication
- Others
- Seems to know everyone
- "I can't get out because of my poor feet"

- Only has one relation
- "Miserable old git!"
- Seducing Prussian Officers
- "Oh bugger"
- Village communities can be supportive
- Outrageous to let her live like that