

***Transforming the quality of dementia care:
Consultation on a national dementia strategy***

**Submission by the
Joseph Rowntree Foundation**

August 2008

The Joseph Rowntree Foundation (JRF) is pleased to submit the following response to the Department of Health's consultation on a national dementia strategy. We would be happy to supply any further information as required.

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The Joseph Rowntree Foundation (JRF) is one of the largest social policy research and development charities in the UK. For over a century we have been engaged with searching out the causes of social problems, investigating solutions and seeking to influence those who can make changes. JRF's purpose is to search, demonstrate and influence, providing evidence, solutions and ideas that will help to overcome the causes of poverty, disadvantage and social evil. The Joseph Rowntree Housing Trust (JRHT) shares the aims of the Foundation and engages in practical housing and care work. A proportion of JRHT's residents – in the Continuing Care Retirement Community, eight care homes, two new extra care schemes and village of New Earswick – are affected by dementia.

JOSEPH ROWNTREE FOUNDATION
Response to the consultation on
Transforming the quality of dementia care

Introduction

This submission is structured to answer, in order, the questions set by the consultation paper, *Transforming the quality of dementia care: Consultation on a national dementia strategy*. The final section covers some areas not directly mentioned in the paper that the Joseph Rowntree Foundation (JRF) thinks warrant the government's consideration in relation to a national dementia strategy.

As part of its work on social policy and practice, JRF has sought to understand and improve the experiences of older people in society. JRF has a unique perspective on issues facing older people, through the interaction of its research, its operations as a provider of housing and social care, and its commitment to conducting a dialogue with older people so that they can articulate their own needs and perspectives. On the one hand, this work has found that many needs are not being met, and that too often older people remain vulnerable to poverty and neglect. On the other hand, JRF's research shows that older people's aspirations are neither excessive nor impossible to meet. Often what they want is security that resources and services will be forthcoming: reliability, together with a "human" face to services, is critical. On its operational side, JRF has shown that it is possible to provide the things that older people consider important, and which will improve their quality of life.

This response is based on our research evidence, our operational experience as a provider of housing and care, and our conversations with older people and carers.

Summary

JRF welcomes the National Dementia Strategy and is very supportive of its aims and focus.

There are a number of issues which, based on our own research and practice, we think deserve greater prominence. In summary, these are:

- The importance of communication and involvement in achieving person-centred care, and the role of training and evidence-based tools in enabling this.
- The importance of involving front-line practitioners in helping to change the culture of caring and promote the social model of disability, especially in institutional settings.
- The need to improve awareness of specific professional groups, such as those supporting people with a dual impairment (learning difficulties and dementia), and night-time staff in care homes.
- The potential role of staff in care homes registered for personal care in diagnosing and addressing health issues in those with dementia.
- More analysis of the role of different settings (e.g. the community, housing with care, personal care and nursing care homes, hospitals) in supporting people with dementia, and on the scope for further development in each setting to enhance choice and avoid the need for unnecessary moves from one setting to another.
- The need for better support in the recognition of pain, and for night-time care staff.
- The importance of involving people with dementia in the research agenda.
- The need for financial support for local learning networks for care providers.
- The need for carers of people with dementia to be fully supported by adequate resources and flexible services.
- The need for people with dementia and their carers to have clarity about what the government offers and what their entitlements are.

Chapter 1 – Improved awareness

Q. Are these outcomes, recommendations and the suggested means of achieving them the right ones?

Overall, JRF agrees.

Q. Is there anything that has been missed to help us improve public and professional awareness of dementia?

JRF research highlights two staff groups who have a specific need for enhanced awareness – those involved with people who have learning difficulties, and night-time staff in care settings.

The draft strategy is clear that the recommended campaign should take account of the fact that the needs of some groups – including those with a learning difficulty and dementia – may be different to those of the rest of the population, and may require specifically tailored approaches. JRF research highlights the importance of raising awareness among people with learning difficulties, their families and staff, about living with dementia. (1, 2) The evidence is that, without this awareness, lack of planning can lead to ad hoc arrangements that fail to meet their needs, or those of fellow residents and staff. This may include inappropriate moves to nursing homes for older people. Good practice in relation to diagnosis and follow-up care is essential. Consistent, quality, practice-based training can be critical in determining the type of care given and the likelihood of someone remaining 'at home'. (The JRF has completed work on staff awareness and training, published as "*In the Know*". (3))

It is worth noting too that staff can and do play down the increasing complexity of an individual resident's care needs, because they fear that a request for additional help might result in the person being moved. This may be one barrier to early diagnosis and support which needs to be addressed very specifically.

Another group whose awareness needs improving is night-time staff in care homes (and, by implication, other settings). Recent JRF research (4) suggests that this group often has less access to training

and awareness than their day-time colleagues, and possibly little or no training on responding to people with dementia, supporting continence, recognising and managing pain, or supporting good hydration and nutrition during the night. Where training is available to night staff, it is often not specifically focused on night-time issues. Yet the way night-time staff respond to the needs of residents with dementia can have a major impact on good sleep, reassurance, nutrition and hydration, and social interaction. Managers and inspectors or regulators also need a good awareness of all these issues.

Q. What can you or your organisation do to help implement the recommendations?

Please see the Recommendations section.

Chapter 2 – Early diagnosis and intervention

Q. Are these outcomes, recommendations and the suggested means of achieving them the right ones?

Q. Is there anything that has been missed to help enable early diagnosis and intervention?

Q. Do you agree that the diagnosis of dementia should be made by a specialist?

We have no relevant evidence to shed further light on these questions.

Q. How open should referral systems to a memory service be? Should people be able to refer themselves, or should they have to go to their GP first?

It would be very helpful if the adviser could be accessible directly to members of the public without referral through the psychiatrist or Memory Clinic. This would be especially supportive for those who are not yet 'in the system' (e.g. wondering if they have dementia); those

who do not have, or do not know, their diagnosis; and those who do not identify with the term 'dementia' (JRF research experience is that this is a very sensitive issue).

Q. How would the dementia care adviser be able to ensure continuity of care?

The proposed role of 'dementia care adviser' is strongly supported by JRF research. (5) This shows that older people welcome advice that helps relate information to their particular circumstances, and assistance to obtain the services they need. However, the volume of information available can be as problematic as an absence of information. Older people do not generally find distinctions between information, advice and advocacy meaningful, valuing information that is topic-based rather than the agency-based information that is more frequently offered. Different modes and styles of information suit people at different times and in relation to different topics. People want timely information, often at a point of change or crisis in their lives, and comprehensive information actively offered in their first language at such stages. They desire continuity of contact, to avoid having to retell their story to new people. A follow-up service is also appreciated, ensuring a solution is achieved, rather than simply being referred on to yet another potential source of information.

The Joseph Rowntree Housing Trust (JRHT)'s operational experience suggests that, as well as supporting individuals and their families, the adviser may also have a role in advising non-specialist staff in a range of settings. JRHT has for a number of years employed a Specialist Dementia Nurse, to provide support and guidance to both care home and housing staff, and residents. Continuity, timeliness and follow-up are key features of the way this support is delivered.

It would also be helpful if the adviser was linked to – and could direct people to – key internet resources, such as the Alzheimer's Society website and Social Care Institute for Excellence (SCIE)'s new 'Dementia Online' (prototype in production).

Q. What can you or your organisation do to help implement these recommendations?

Please see the Recommendations section.

Chapter 3 – High quality care and support

Q. Are these outcomes, recommendations and suggested means of achieving them the right ones?

Q. Is there anything that has been missed that would help to ensure high-quality care and support for people with dementia and their families?

The draft strategy does not sufficiently comment on the range of settings currently available for people at different stages of dementia, or distinguish between, for example, home care and housing with care or extra care settings, or between residential care and nursing home care. Nor does it comment on the scope for further development in each to enhance choice and avoid the need for unnecessary moves from one setting to another – often a cause of major stress to the individual concerned and their family.

With regard to care at home, the document is clear that most people want to remain in their own homes for as long as possible, stating that: *“all too often, people with dementia (particularly older people) find themselves on a conveyor belt that takes them into long-term residential care because it appears that there are no alternatives available.”* This is completely in line with JRF’s research findings, that disabled and older people should have an entitlement to independent living. Choice and control over any assistance required is critical to independent living, and for many this will also mean that they want to live in their own home. The structure and resourcing of social care should not force people to leave their home in order to get what assistance they need.

However, enabling people to stay in their own homes requires much more than providing a network of memory services and dementia advisors. Crucially, it is also about ensuring that people have access

to a wide range of 'low-level' services. JRF research shows that many older people remain isolated – living in one's own home with no support or contact can be as disempowering as the stereotype of a nursing home. (6, 7) Older people see health as much broader than simply treating illness – it is about being able to have a laugh, keep mentally active, do things which interest you, and meeting friends. (8, 9) The forms of support or services which older people value concern negotiating the ordinary things in life – relationships, learning in later life, transport, housing, contact – in their words, “being comfortable”, having “that bit of help”. (8–14) These values and concerns apply to those with dementia as much as to the wide cohort of older people in general, and are crucial if more people are to be enabled to stay at home.

The current popularity – and Government funding – of housing with care settings, including Continuing Care Retirement Communities and extra care schemes, makes it likely that more people with dementia will reside in such settings. Although these schemes may have much to offer people with dementia, the research evidence base for this is still very scanty. (14, 15) What evidence there is suggests that there are tensions around the capacity of such schemes to accommodate individuals with high levels of care needs, while remaining true to the concept of promoting independence in later life. While schemes can provide an alternative to residential care for some people in some circumstances, the evidence consistently reports numbers of people – typically those with dementia-type illnesses and/or challenging behaviours – moving on from housing with care into both residential care and nursing homes.

JRHT brings its own operational experience to the issue of what retirement communities can contribute to older people's well-being. It has evaluated its own Continuing Care Retirement Community at Hartrigg Oaks, (16) and has also looked more widely (17) at what benefits such models bring to their residents and surrounding communities. The idea of a Continuing Care Retirement Community is to allow people to buy into a package covering their future care needs without moving: care is on hand within the community, as is residential care for periods when it might be required. Over the coming years, JRHT's major new retirement village at Hartlepool will

further test out the extent to which this model can meet the needs of those who come in with or develop dementia.

A further question relates to the extent to which registered care homes can and should enable those with dementia to stay, rather than being transferred to a nursing home setting or a hospital.

An evaluation of an initiative aiming to meet the nursing needs of residents within a residential care home (18) found that hospital admissions and nursing home transfers could be prevented by training staff in basic nursing. Care home staff and managers preferred residents to be able to stay in their current care home when they were ill, as did the residents themselves. This study suggested that non-nursing care home staff can play a stronger role in early diagnosis and intervention, through support and training to take on new health-promoting roles. This is challenging at first, but confidence and professionalism do grow, enabling staff to more easily identify early signs of health problems (not always picked up in people with dementia because of communication difficulties). This has important benefits, including early intervention and improved quality of life for the resident, and cost savings by avoiding transfers to a nursing home setting or a hospital.

JRHT is also trialling in one of its own residential care homes (Bedford Court in Leeds), a new approach to determining and meeting nursing need without requiring older people to move. A Nursing Care Co-ordinator assesses, plans and co-ordinates nursing care, drawing on the flexibility of new skills among care staff. However, the wider adoption of such a model would clearly require a change in policy on the registration of homes.

A further point in relation to care settings, which is not mentioned in the draft strategy, is the importance of design. JRF research (19) showed that the early stages of planning and setting up a new care home or unit are crucial in laying good foundations for future practice: investment in good design benefits residents, staff and the business. Good planning includes:

- ensuring plans match local needs;
- developing a clear service model according to local circumstances;

- developing the service model and building design in tandem; and
- ensuring sites have good access to community facilities and good public transport.

JRF and Habinteg's work on Lifetime Homes, (20) although not specifically related to dementia, is also relevant in any discussion on design. Sixteen design standards, which have now been reflected in the code for sustainable homes, help to ensure that the home is flexible, adaptable and accessible, and adds to comfort, convenience and safety. Crucially, because these standards are applicable to *all* (new) housing, achieving them allows older people to remain in their familiar home environment – of particular importance to those who go on to develop dementia.

Q. What more could be done in acute care, home care and care homes?

JRF research highlights two areas which may need greater profile in the strategy.

Firstly, it is essential that attention is paid to what happens at night in care homes. A JRF study of night-time care (4) showed that, while care homes offer a 24-hour service, night-time staff often miss out on training and support, and that this has knock-on effects for the residents' quality of life. Improving the quality of night-time care is essential in the overall task of making care for people with dementia in care homes better and more person-centred. JRF evidence suggests that this will require home managers to:

- implement regular communication and support strategies between managers and night-time care staff;
- monitor and address staff training requirements;
- allocate to each resident a night-time key worker who produces and reviews their night-time care plan; and
- ensure the night-time environment is enabling, not disabling, for residents.

The action research part of this study showed that even relatively minor changes in practice, at low or no cost, could result in considerable improvements to the night-time care experience.

The study also highlights the need for regulatory bodies to include night-time inspections as standard, not just as the result of complaints, and to ensure that inspectors themselves have a good knowledge of dementia.

Night-time care is also an issue in care settings for people with learning disability and dementia. Another study (2) showed that, in such settings, the employment of awake (as opposed to sleep-in) night staff is essential, not only for dealing with night-time disturbances but also for providing one-to-one support. This support can also have a positive impact on fellow residents' ability to accept and cope with the person(s) with dementia – meaning that they are less likely to have to move on to a different setting.

JRF would also like to see a reference in the strategy to the importance of training and awareness of staff around pain recognition. There is evidence (21) of a concerning level of unrecognised and, therefore, untreated pain among people with learning difficulties who also have dementia. Staff attitudes towards, and experience of, 'behaviour that challenges', problems around communication, beliefs about pain thresholds, the impact of past treatment of some people with learning difficulties on their willingness to complain of pain, and the use of agency/bank staff, all contribute to a low level of pain recognition. Better training of staff at all levels in all relevant professions about dementia and learning difficulties is required, and, in particular, training about the pain management needs of people in this group and the use of pain assessment tools.

Q. What could be done to make the personalisation of care agenda (including individual budgets) work for people with dementia and their family carers?

People with dementia often experience communication difficulties. The strategy consultation document refers to the recent Commission for Social Care Inspection (CSCI) study, which has shown that the

quality of staff communication with people with dementia has a major impact on their quality of life. It also states that:

... assessing the real-life experience of people with dementia is an important part of the inspection process, and listening to their views should be part of any assessment of quality ... Specific efforts need to be made to ensure that all inspections include monitoring the experience of those with more advanced dementia or compromised communication needs.

JRF would like to see more in the strategy about the importance of communication with and involvement of people with dementia – and greater recognition of the needs of front-line staff for a range of communication tools and skills at their disposal. Personalisation can only be achieved if people are involved as fully as possible in decision-making about their care and treatment options, and about key life transitions. Research by JRF on the experiences of people with dementia (22) has illustrated both the importance of enabling them to communicate their views, and the training and support needed by staff in order to work in such person-centred ways. If the strategy is to deliver its vision, it is very important that workforce training pays particular attention to the skills required to enable people with significant communication and/or cognitive impairments to exert choice and control.

However, service settings are complex environments in which it is often difficult for staff to find opportunities to undertake communication and consultation work, and to follow through on plans. It is necessary both to address aspects of the organisation which act as barriers to communication, and also to support staff in utilising opportunities which present themselves spontaneously. The study (22) found that a range of consultation approaches, both verbal and non-verbal, was effective for different individuals at different times and in different circumstances.

Communication with people with dual impairment – learning difficulties and dementia – can be especially challenging. JRF evidence (1) shows that both staff and families have a key role to play in 'preserving' and maximising such people's involvement in everyday matters and future planning. Most people are able to express clear

preferences, even if they do not use speech to communicate. However, there are variations in the opportunities available to people to make choices – most have some degree of choice over everyday matters, but these are often restricted, partial or contested choices. The attitudes and behaviour of staff and families influence individuals' opportunities to make choices. There is a need for more time, resources and appropriate training to support staff and family in promoting people with dual impairment's ability to make choices.

'Talking Mats' are tools which appear to have important potential in the area of communication and choice-making with people with dementia. JRF research (23) found that conversations using Talking Mats were more effective for people with dementia than both unstructured (ordinary) or structured conversations. Using the mats, improvements were evident in the participants' understanding, engagement, and ability to keep on track and make their views understood. This tool may therefore be helpful in allowing them to express their views about a wide range of topics in a variety of situations more easily. Although more research is needed on this, it seems that Talking Mats may also have the potential to help people with dementia to:

- tell family and staff how they feel;
- provide information on their views to medical and social work staff and inspectors;
- help people with early- (and perhaps moderate-) stage dementia when they face difficult decisions; and
- extend the period during which people with dementia can play an active role in making decisions about their lives.

Chapter 4 – Delivering the National Dementia Strategy

Q. Is there anything that has been missed to help us deliver the National Dementia Strategy?

Although training is a key feature of the strategy, JRF would like to see greater prominence given to the involvement of front-line practitioners in helping to change the culture and value-base of institutional care settings. JRF research (24) shows how the relationship between the service user and front-line worker is pivotal

to the experience of good quality person-centred care and support. Service users greatly value the personal qualities of staff, such as patience, compassion, sensitivity and empathy. But management practices tend to overlook the importance of these relationships; front-line workers often feel they receive little support from management in their day-to-day work. Barriers to the delivery of person-centred care predominantly relate to bureaucratic structures: a move towards increased management and budget-led services constrains front-line workers.

It is also crucial that training is underpinned by an understanding of the social model of disability; the concept of independent living must be integral to improving the skills and capacity of the social care workforce. JRF has funded a considerable amount of research (25–27) on the implementation of direct payments and other initiatives intended to increase choice and control for people who need support (such as Person Centred Planning). All of this research has found that an understanding of disabling barriers and a commitment to promoting choice and control are crucial among social care workers at all levels. Without such understanding and commitment, the goal of independent living will not be achieved.

The strategy mentions “encouraging the development of clinical networks to support service improvement, share learning and spread good practice.” JRF’s view is that there is also a need to support learning networks among *non-clinical* practitioners, in particular front-line social care staff (community and residential), and also housing staff (e.g. sheltered housing wardens).

An example is York and Selby Learning Network for Dementia, which was set up in 2004 to improve access to and sharing of information and best practice on dementia. This need was identified by local independent care providers – residential, nursing, specialist elderly mentally infirm (EMI) care homes and domiciliary agencies. Feedback from members has been very positive: they value the confidence they get from discussing problems and opportunities with other care professionals, the freedom to speak confidentially in a non-judgemental forum, and learning from the speakers and each other at the sessions. However, although the Network only requires £2,000 per annum to meet its costs, it had a funding crisis last year (JRF has

now agreed to provide two years' interim funding). Government support for such low-cost, high-value initiatives is crucial if they are to continue and be sustainable. Such networks would also benefit from greater co-ordination and status – the current situation is that, although they are springing up around the country, they remain essentially unconnected with each other.

Finally, no strategy can be effective without sufficient resources to underpin its implementation. A JRF review of the financial care model in Scotland (28) demonstrated that clarity about entitlements is vital to the success of any new system of care. The evidence shows that, in Scotland, providing a co-payment towards the costs of care has freed unpaid carers of those with dementia to perform more social-type tasks, and therefore supported people to remain at home for longer.

Recommendations

Q. What can you or your organisation do to help implement these recommendations?

On the research side, the Joseph Rowntree Foundation is:

- Completing work about older people's choice and control in residential and nursing care. This project looks fundamentally and practically at the present system.
- Scoping a major new research programme focusing on residential care for older people with high support needs (including dementia).
- Planning further research on housing with care, which is likely to include looking at whether such housing can really offer a 'home for life' for people with dementia.
- Funding several relevant research studies – for example, looking at the effectiveness of Talking Mats for couples making decisions about daily living; looking at social well-being in extra care housing; and soliciting the views of older people and carers from ethnic communities in Bradford.
- Funding a programme of training on Talking Mats for people with dementia, across the four countries of the UK.
- Disseminating the messages of our recent study on night-time care, and considering further research and dissemination on this issue.

On the operational side, the Joseph Rowntree Housing Trust is:

- Working with the Alzheimer's Society to create a new learning programme – a complete revision of the previous basic dementia care learning programmes 'Yesterday, Today, Tomorrow' (2002) and 'Introduction to Quality Dementia Care' (2005). The latter programme was originally supported and tested by JRF. The new programme will combine the best features of both the previous ones and incorporate some of the latest thinking in dementia care support. It is divided into three levels, and will include film, group

exercises, case studies, self study and reflective practice. It is being designed for use by staff groups working in a service, or for self study on-line or using a CD-ROM. We will be piloting the course in our settings.

- Continuing to support our own care staff and residents through the provision of our Specialist Dementia Nurse.
- Providing two years' interim funding for the local York Dementia Learning Forum, and supporting its development through the involvement on the steering group of our Specialist Dementia Nurse.
- Reviewing arrangements for those residents at our retirement community, Hartrigg Oaks, whose needs are growing due to dementia – this includes looking at the impact of their needs on the care home and the domiciliary care service.

Research gaps

JRF welcomes the proposed strategic review of national dementia research. This will help to inform our own research agenda. A recent JRF-funded event on *'Enhancing the What Works research knowledge base on dementia care and housing'* highlighted a number of gaps around:

- buildings and the environment;
- matching services to need;
- early intervention;
- psycho-social intervention;
- knowledge of existing evidence; and
- change management. (29)

Discussion from the event also prioritised some key, overarching themes – such as cost effectiveness in the context of maintaining quality of life; experiences from, and views of, people with dementia; focus not only on day-time care; co-morbidities and co-existing impairments such as sensory loss; and research ethics. This event has led to the establishment of a new research consortium of housing associations with a special interest in dementia.

We have also identified major gaps in the research evidence on residential care, a sector which we fear is at risk of becoming increasingly residualised with the current focus on care at home, and on other housing with care models.

Finally, JRF would wish to promote the involvement of people with dementia themselves in the national strategy research programme. This is a difficult but very important area. There has been a great deal of work with people with learning difficulties, and more generally with people who have cognitive or communication impairments. But it is still the case that the expectations of involving people with dementia in policy, planning, practice or research remain quite low. There is a need to develop their capacity and learning.

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