Models of community support for people with dementia
Where does the CMHN fit in?

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Introduction

Most people with dementia live at home, this is where they want to live, this is where their families want them to live, and this is where the government wants them to live.

(Graham 2003)

Community care has, in all meanings of the word, become big business. However, lengthening the time that people with dementia spend at home is not necessarily the most appropriate indicator of success or quality of life for all concerned. As an outcome, it fails to appreciate whether or not the person with dementia finds life organized around a ‘care package’ a satisfying experience, and sight may be lost of the fact that for many people with dementia, admission into a care home can be a positive choice and a rewarding experience. Despite these concerns, community care is ‘here to stay’ and this chapter explores some of the tension, issues and opportunities around its socio-political rise in importance in the health and social care field, its current provision and future profile. Allied to this exploration is an analysis of the role that the community mental health nurse (CMHN) can actively play in promoting quality of life for people with dementia, and their family networks as they make use of the available support services.

Community care: the changing landscape

The development of traditional asylums has its roots within the successful economic boom of the Victorian era, coupled with a desire to fund what was for the time an enlightened and humane approach towards the ‘mentally ill’. This asylum tradition has meant that for the greater part of the twentieth century the provision of mental health care was dominated by institutionalization and institutional caring practice (Nolan 2003). From the 1960s onwards, this landscape began to change with less political enthusiasm to financially maintain the institutions and a growing perception that less expensive and more individualized options were available (Turner 2004). Plans were outlined in the early 1960s to restrict hospital services to providing only acute psychiatric care, while responsibility for
continuing care (within a community model) would pass to the local authority (Ministry of Health 1963).

Supporting this process of change were evolving criticisms about the stigma of mental illness, the negative impact of ‘institutional neurosis’ and the neglect, abuse and inadequate care practices commonly associated with the mental hospital (Jones 1993). In coining the term, the ‘old culture of dementia care’, Kitwood (1997) later described and condemned the impact of such practices upon the very personhood of people with dementia living within these environments. Notwithstanding the impetus, and need, for services to be provided outside of the closed world of the asylum, it is clear that community care options have never been adequately funded. In alluding to this, the Griffiths Report (Department of Health 1988) offered the illuminating analogy that community care was ‘Everyone’s distant relative but nobody’s baby.’

Following hot on the heels of this report, the Caring for People White Paper (Department of Health 1989) called for no further hospital closures until ‘a funded community-based alternative was in place’. Paradoxically, there was no central provision of funding established to develop community services while asylums were sold and redeveloped. Through the mid to late 1980s market forces influenced the provision of community care and the private sector offered services at a lower cost than institutional care. The steep decline in National Health Service psychiatric bed numbers in the decade from 1982 was mirrored, and possibly exceeded, by an increase in provision within the private residential and nursing homes sector (Davidge et al. 1993).

Now, virtually all the ‘traditional’ mental hospitals have now closed with the long-stay residents having died, drifted into homelessness or more typically been absorbed into community-based care facilities. With this change the previous dominance of the institution has disappeared and been replaced by an overwhelming belief in the value of community care and support. Concerns are, however, being expressed that although this has largely been a positive and bloodless coup, vestiges of the old regime remain very much at the heart of care provision. For instance, Holloway (2004) collectively describes all community care provision as simply forming a ‘virtual asylum’ reflecting concerns that realizing the potential of person-centred care with the ideals of autonomy and empowerment is restrained by an old cultural resistance to, and fear of, change from those who deliver the care (Edwards 2004).

By clinging on to the ethos of the ‘old’ regime, it can be seen how the traditional model of community support (see Figure 1.1) influences the current landscape and prevents change from occurring. At the apex of the support pyramid are the two domains, acute care (crisis management) and the frail older people (dependency management), that attract the greater proportion of available resources.

While these are, indeed, deserving of attention, their dominance suffocates any attempt to intervene at an earlier stage to either prevent crisis or to improve the (mental) health and well-being of older people more generally. What emerges is the maintenance of stereotypes that in turn maintain an ageist agenda towards service provision. As an example, cost ceilings on care packages are so much lower in comparison to adults of working age, that older people receive only ‘safety net’ services and are forced into residential care earlier than should be the case (Joseph Rowntree Foundation 2003).

It must also be acknowledged that this change agenda has had an overall impact on the practice of the CMHN. Banerjee and Chan (2005) have rehearsed these arguments and began by reflecting that the deinstitutionalization process has led to the number of
continuing care beds in a hospital setting being ‘tiny’ in comparison to numbers available in the past; an outcome that has implications for people with dementia requiring general nursing care. In equally small numbers are the acute admissions beds available to older people with mental health problems. Consequently, the threshold for severity of illness, which triggers admission, has significantly risen, and usually only those people who present with the ‘highest levels of risk’ may be admitted into hospital.

This reduced provision has a number of implications that, unless solutions can be found, will potentially prevent change from occurring. For example, people with dementia are now experiencing rationing of services on the basis of severity of illness or risk, with the bulk of community support provision going to those at the apex of the support pyramid (Figure 1.1). The opportunities to engage with people at an earlier stage of their condition become fewer and the traditional model of support is therefore perpetuated. This is despite a policy agenda that is aimed at early intervention (DOH 2001). There is potential for the resources of the CMHN to be increasingly targeted towards those people with dementia who present with high levels of risk and disturbance, yet are below the threshold for receiving hospital care. Only in the most ‘severe’ cases will specialist mental health services be involved, and far greater community support will be provided by primary care, social services or other agencies. It is with these issues and concerns in mind that we will now consider the current provision of community support services in the UK.

Models of community support provision: a contemporary appraisal

Over time, the experience of living with a dementia leads to a high level of dependency and a reliance on care services (family and/or service-based) to maintain personal integrity and esteem. In acknowledging this, it may be considered that the move towards
community-based services is not an alien concept to most old age psychiatric services. For instance, Arie (1970) set out the fundamental principles that have subsequently come to influence the development of such services across the UK for more than three decades; high on the list is the importance of assessing, treating and maintaining people in their own homes. We now explore some of the models of community support that are currently available to/for people with dementia and uncover areas where the CMHN is making an active contribution.

The family

It is one of the paradoxes of dementia care that the family carer is at one and the same time the greater provider and user of community support services. By far the greatest contribution to maintaining people with dementia in their own homes comes from the family of the person and the move towards deinstitutionalization, as outlined earlier, has increased this responsibility. It is estimated that the value of services provided by unpaid family carers, about £57 billion, equates to the same amount of total healthcare funding for the UK over a 12-month period (Alzheimer’s Society 2004), and that some two million carers devote at least 50 hours per week to this voluntary activity (Office for National Statistics 1995). While services provided by the family may be played down as simply a natural or normal extension of the family relationship, they have become essential to maintaining people with dementia in the community and are highly influential in terms of outcomes. It is recognized, for example, that those people with spouse or daughter, acting as carer, are significantly less likely to enter institutional care than those with other or no carers (Melzer et al. 1997).

It is also well established that the caring role can be arduous with frequently documented stress, increased psychological morbidity, diminished social life, reduced employment prospects, exhaustion and ill-health. The family carer becomes as much ‘at risk’ of social isolation as the person with dementia and while there are limits, particularly increasing behavioural disturbance, for example, much of the research draws attention to the increased commitment and sense of obligation found among spouse and daughter carers (Levin et al. 1989). It is also important to balance this rather negative construction of the caring experience with the rewards of caring that are seen and reported by carers of people with dementia, particularly in the areas of maintaining the dignity of the person with dementia, sustaining their general sense of ‘happiness’, tending to their needs and ability to give the ‘best’ care possible (Nolan and Keady 2001: 167).

If carers are adequately supported within their role, then people with dementia may live at home for much longer. On the other hand, support means that a range of services to meet family needs and expectations has to be in place and that an emphasis on promoting family empowerment and adaptive coping moves beyond the rhetorical and into the practical. The challenge often comes when resources are patchy, ineffective or non-existent (Graham 2003). Accessing support for family carers is fraught with potential difficulties. The GP may often be the first port of call but may well not fully perceive, or accurately estimate, the extent of difficulties, may not be convinced of the value of community support provision or may not adequately know what kind of support is available (Pollitt et al. 1991). If referral by the GP is problematic, then self-referral by the carer is seen as being potentially ‘hazardous’ (Bruce and Patterson 2000) as many will be easily discouraged, or confused, when presented with inadequate information or inappropriate signposting.

Timing of a referral to social services to allow carers to access an array of community support options is also often problematic. For example, carers may feel ‘压 make too many demands on their time’ (Pollitt et al. 1991). This is a common perception, often shared by carers, that their needs are not being recognized or met. Carers report that their needs are often overlooked and that they are not provided with the time and resources to maintain their own personal lives and health. It is estimated, for example, that unpaid carers lose as much as two thirds of a year of their personal lives to caring (Office for National Statistics 1995).
support has to be correctly judged. The whole issue of involving outside care providers of any kind signals a watershed in the caring experience. If it is presented too early, it can be damaging to the morale of the carer, especially when allied to concerns about how the person with dementia will react. Similarly, delaying referral may mean that the support on offer is simply ‘too little, too late’ to impact upon the severity of problems and challenges. As Alison Soliman (2003) demonstrated in our previous book, CMHN support geared explicitly to the needs of family carers can have a positive impact upon the quality of life of the person with dementia and benefits the family system.

Early intervention services

Increased social awareness of dementia, improved diagnostic services and the arrival of potential drug therapies have meant that increased numbers of people are receiving a diagnosis of dementia at a much earlier stage than at any other time. While such a move reflects what people with dementia have said they want (Pratt and Wilkinson 2001), it raises needs and expectations that the traditional model of support cannot realistically meet. Alzheimer’s Scotland – Action on Dementia (2003) has previously articulated these needs as including the provision of relevant and accurate information, the meeting of emotional needs and the provision of appropriate social support. These needs are probably universal to all people with long-term conditions, but if we consider that the profile of people known to have dementia and their supporters is changing, then it follows that their needs may best be met well before a crisis point is reached. Greater emphasis is therefore being placed upon the early introduction of support to promote adjustment and coping with the diagnosis, and emerging symptoms. Box 1.1 outlines a range of interventions that may be used to provide this support.

The early introduction of appropriate medical treatments alongside psychosocial interventions not only improves the well-being of people with dementia, but also potentially reduces carer stress to an extent that the need for residential care may be postponed. Early intervention services are therefore specifically designed to support people through the early stages of a dementia and are rooted in the move towards crisis prevention (Department of Health 2001).

**Box 1.1 Early interventions for people with dementia and their supporters**
- Diagnosis.
- Pharmacological therapies.
- Accurate information provision.
- Counselling and emotional support.
- Support groups.
- Rehabilitation programmes.
- Advocacy services.
- Support or befriending.
- Aids, technologies and adaptations.
One of the best examples has been the Dementia Advice and Support Service (DASS). Established in 1998 by the Mental Health Foundation, DASS operates across the UK through a small number of pilot schemes. Each scheme provides a domiciliary-based service to people who have received a diagnosis of dementia. The minimum ranges of services are: the provision of information, advice, support, signposting and befriending. Additionally, some schemes offer complementary services such as respite, advocacy or counselling and their overall aims are presented in Box 1.2.

Services aimed at post-diagnostic counselling form one area of early intervention that is growing in prominence and, as this (see Chapters 8 and 9) and the previous CMHN dementia care text revealed (Page 2003), can be undertaken by the CMHN working in specialist settings such as in the memory clinic. As an intervention, post-diagnostic counselling is drawn, almost exclusively, from the work of Yale (1999) and aims to promote the notion that people with dementia are able to use strategies that allow them to ‘take on their diagnosis’ and ‘work it through’, emphasizing the aspiration of reaching a point, and life, beyond diagnosis. The intention of support would therefore appear to be inherently prophylactic, utilizing educational and psychological mechanisms to enhance coping strategies. Clear comparison can be made with the nature and psychological processes of palliative care support services and in this respect the promotion of problem-focused solutions, rather than emotion-based ones, is the desirable outcome. Arguably, post-diagnostic counselling may therefore represent a vital element in the early introduction and development of a palliative care approach towards the experience of living with dementia.

There appears to be agreement that meeting in groups affords the opportunity for meaningful discussion and aligns with the goals outlined above. What needs to be reinforced, though, is that not everyone is comfortable with the group format (Yale 1999) and therefore the CMHN, as an experienced and confident practitioner, can use a post-diagnostic counselling process with an individual person or family. Where they are used, group sessions may be structured, unstructured or a combination of both and most programmes use some component of education alongside the opportunity for participant-led dialogue.

As to the efficacy of the group approach, Bender and Constance (2005) argue that

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<th>Box 1.2 DASS project aims</th>
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<td>- Improve the availability of information, advice and support to people in the early stages of dementia and their families.</td>
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<td>- Extend the period of community-based living for people with dementia.</td>
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<td>- Promote user and carer well-being and help users and carers ‘manage’ dementia more effectively.</td>
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<td>- Develop a range of practical, replicable models of service delivery.</td>
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<td>- Increase the involvement of GPs in diagnosing and treating dementia in its early stages.</td>
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<td>- Act as a catalyst for extending the network of services available.</td>
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<td>- Develop a body of knowledge about the role and effectiveness of early intervention for older people with dementia, including ethnic minority elders.</td>
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<td>- Demonstrate the potential for using volunteers alongside paid staff.</td>
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benefits of participation can be viewed from the perspective of the leaders, the relatives and (most importantly) the participants. They found that group participation was for some the only regular social contact, reinforcing findings from Mason et al. (2005) that the most significant benefit, for participants, was framed in terms of the social network that group participation facilitated. This was in direct contrast to the multiple social losses being experienced in the participant’s everyday lives, and the role of the group in the maintenance of a sense of self was seen as crucial.

Social care

While overall social care provision encompasses a broad array of activities from home helps to nursing home placement, this section considers those services that are collectively referred to as ‘home care’ – essentially, the provision of assistance with domestic tasks or personal care provided through social services or a care agency. The focus is upon those tasks and activities that are central to the older person being maintained at home and the intensity of the service is measured by virtue of the amount of time the service is required by an individual and calculated through ‘contact hours’. A little help to many people in need is of enormous significance to people with dementia who live alone and to family carers who are encountering difficulty of some description. Currently, more intensive home support is quantified as the requirement to provide more than five contact hours per week and six or more visits per week.

A review of demands placed upon community support services by people with dementia (Alzheimer Scotland – Action on Dementia 2003) estimated that there are 1,100 people with dementia within a population of 100,000. Of these, 60 per cent live at home and almost all are in receipt of some kind of community support. The largest group (63 per cent) required only a standard service that includes some help with personal care or the use of day centres, whereas the smallest group (6 per cent) required more intensive packages of care. It is this 6 per cent of people with dementia who are struggling to remain at home and who may require almost constant supervision, who have personal needs which will need to be met day and night, and whose main carer will need the support of planned respite or input from specialist CMHN. Because the traditional model of service coordination places significant demands upon the family carer, it is unlikely that people with dementia living alone could be effectively maintained at home even with this high degree of support, and it would not be uncommon for them to experience earlier admission into a continuing care home. Additionally, the reality of home support is often poor. The independent provision of domestic care services has proliferated over the past decade and this may have been at the expense of quality and training (Godber and Rosenvinge 1998). A vital role for the CMHN emerges in terms of vigilance for indicators of abuse, whether intentional or otherwise, advocating on behalf of people with dementia and advising domestic carers about appropriate behaviour, communication approaches, daily living skills, and so on.

In responding to problems in service delivery, some non-statutory agencies, predominantly housing associations, have recently started to turn their attention to increasing the amount of support they can offer to their tenants who may have particular needs. An integrated in-house model of support ‘Extra Care’ is offered by the Anchor Housing Association (Tench 2003) and views a single provider of both housing and care working in partnership with external providers, such as GPs and pharmacists. The key principle of
'Extra Care’ is to provide people with dementia (among others) with housing specifically designed to promote social inclusion and maximize independent living. Instrumental to this philosophy is the availability of a 24-hour domiciliary care team with the ability to respond to an individual tenant’s changing needs. Overall, the ‘Extra Care’ model is influenced by interdependence, particularly in relation to decision-making regarding tenancy offers or managing relationships with neighbours. Interdependence also emphasizes the importance of commitment from all stakeholders, thereby ensuring that people with dementia are appropriately placed and supported in the community setting.

In adding a mental health dimension to home support, Murphy (1997) has differentiated between two different types of care needs which she terms ‘ordinary’ and ‘special’. Ordinary needs are those required by every citizen and include such things as: a place to live, companionship, protection from harm, meaningful occupation, meals, etc., and this would fall within the remit of the social care provider. Special needs are those that are generated directly by a mental illness, they are those things that specialist mental health services would provide and include: medical treatment, psychological treatment and rehabilitation.

Placing these in the context of home support, Lawley and Inasu (2003) describe an intensive home support service for older people with mental illness which aims to address these special needs and by so doing prevent hospital admission. Audit of the service provided mixed and interesting results. People with a dementia and severe psychiatric symptoms associated with increased risk could be effectively maintained within the community when they would otherwise have been compulsorily detained in hospital. The negative effect of this was that again the severity threshold for admission was raised and consequently expectations were placed upon other community support providers to participate in managing more seriously ill people. A proportion of the intensive support team’s time was therefore reallocated to training and supporting these other providers.

A further finding was that some patients who needed admission had this delayed until a greater crisis was reached. Previously, Richman et al. (2003) found that where preventing admission is used as a successful outcome measure, then the act of admitting a person to an assessment ward, or similar environment, becomes seen as a failure. Consequently, the CMHN may start to adopt a stance that is more about preserving his or her own self-esteem than it is about the best interest of the patient, and the finding underlines the importance of clinical supervision for the CMHN when taking on new and challenging roles.

### Rehabilitation and intermediate care

It is suggested that much rehabilitation work associated with Old Age Psychiatry occurs not in the community but in the few remaining hospital beds that psychiatrists have access to (Bullock 2002). In the short term, this is related to time-limited admissions into acute admissions beds for people who develop another coexisting mental health problem, such as severe depression. The emphasis is upon regaining stability over illness symptoms, with achievable goals for dictating discharge back into the community being identified on admission (Bullock 2002). Long-term rehabilitation in this context is used to describe admissions into NHS ‘continuing care’ beds for a period of time longer than 12 weeks, while the patient is subject to a goal-focused intervention rather than being the recipient of continuing care.
Introducing a concept of rehabilitation to dementia care has a number of advantages. First, it redefines the use of the NHS continuing care beds as rehabilitation beds. Accordingly, it challenges the acute sector to cease perceiving them as the appropriate place to move on the ‘bed blockers’, a pejorative term used to describe older people, some with dementia, who, while fit for discharge, have no community or residential provision available. Second, and more fitting for the context of this chapter, it shows that rehabilitation is possible for people with dementia and raises their profile as being equal recipients of intermediate care. In placing people with dementia into the context of intermediate care, we naturally return to the theme of community support.

The Nuffield Institute (2002) claim that people with dementia who have been admitted to general hospital care are too easily moved on to the residential home sector instead of being assisted to return home. At the heart of this is the poor care that many receive in acute hospital wards. These are frequently cited as over-medication, dehydration and communication failure, leading to deteriorating physical health and consequently to deterioration in mental health. Associated with this are the attitudes towards dementia, which are found in the traditional model, that is, people with dementia are vulnerable, burdensome, problematic, draining of resources and incapable of rehabilitation (Godfrey et al. 2004).

Moreover, there are deficiencies with the current ethos of intermediate care with few rehabilitation opportunities being offered to people with dementia, despite the concept of intermediate care being enthusiastically supported in political terms (Department of Health 2001) and receiving an annual budget in the region of £900 million. This disparity is claimed to be due to intermediate care staff having limited experience of mental health problems and inadequate assessment skills which may lead them to conclude that those with dementia cannot benefit from rehabilitation (Nuffield Institute 2002).

This negative stance is rejected by Gilliard (2003) who advocates that there are many skills and abilities which can be relearned and not only can people with dementia return home but also their vulnerability to further transition can be prevented. In further promoting this viewpoint, Dementia Voice (2002), the Dementia Services Development Centre for the South West, have developed a framework for developing intermediate care services around the needs of people with dementia. They begin by stating the aim as being:

To enable people with dementia to retain or regain abilities where the loss of these abilities would lead to significant change in their quality of life, and/or living arrangements, and such change would not be consistent with their understood wishes.

(Dementia Voice 2002)

Intermediate care for people with dementia is therefore no different than it is for any other older person. Interventions are targeted at times of transition when existing living and support arrangements are breaking down and when it is indicated that intervention can prevent such breakdown. It may, however, be different in that a specialist mental health practitioner should manage its coordination. This is an acknowledgement of the extra dimension that dementia brings to the situation and the essential requirement for both risk assessment and decision-making to be influenced by holistic, person-centred practice.

Clearly this creates a role for the CMHN to be attached to existing intermediate care teams and to coordinate or case manage rehabilitation for people with dementia. By doing so, it may be that not only do people with dementia achieve a greater equity of access to rehabilitation leading to greater opportunities to return and remain home, but also that their participation in decision-making is enhanced. One concept that might be useful in
building a bridge between practice reality and academic thinking is that provided by McCormack (2003) who introduces the concept of ‘authentic consciousness’ as a method for assisting older people to reach decisions that are their own rather than influenced by external pressures, such as worries of family members or demands from acute care staff. Achieving authenticity in decision-making is rooted in values, of a right to self-determination, and activities, focused on the therapeutic relationship, which are to be found at the core of the professional practice of mental health nursing and as such may come easier to the experienced CMHN.

It may also be argued that while the CMHN has become active in supporting the residential care and nursing home sector to better understand and respond to the needs of residents with dementia (Furniaux and Mitchell 2004), there is little in the way of complementary provision to hospital wards. This liaison role is a clear and present opportunity for service development and an augmentation to the CMHN role.

### Day care

The aim of day care is to provide a service that offers some relief to home care providers and an alternative means of respite for carers of people with dementia. In addition to this, it is strongly advocated that day care should be designed to offer something of significance to the person with dementia, whether this be to relieve distress, disability exclusion or isolation (Murphy 1997). Traditionally, these services have been provided by both the health service (day hospitals) and social services (day centres) and both have been not too dissimilar. However, as we have argued, times have changed and the two types of service provision are now much more distinct.

The day centre has a clear focus on the provision of long-term community care and offering people with dementia some structure to life and opportunities to engage in meaningful and purposeful activity, while also providing carers with vital time apart. The day hospital remit has changed and become more associated with aiding the assessment process and treating acute mental health problems which would otherwise warrant institutional admission. The day hospital also provides psychotherapy, behavioural intervention and monitoring of pharmacological therapy regimes and its long-term support provision is targeted towards those who are ‘at risk’ of relapse (due to a coexisting functional illness), or those whose needs may not be fully met by the day centre.

While both services offer much to people with dementia, one of the commonest challenges faced to their use is that of the person’s refusal to attend. Frequently, this is described as being a consequence of loss of insight due to dementia (Fairburn 1997) that culminates in rejection, or restriction, in the care package being delivered, increased caregiver burden and potentially earlier admission to care. Alternatives have been proposed to the ‘insight assumption’ that may act as a further element of blame and stigma. Keady and Nolan (1994) proposed the adjustment stage of ‘suffering in silence’ whereby people with dementia, although acutely aware of changing abilities, are not psychologically prepared to be open with others about this and consequently appear to be in denial. Moreover, it can be that people with dementia, or their families, make an informed decision that they simply do not want this type of service in their lives.

Recognizing that refusing the offer of day care is not simply an ‘insightless act’ but, perhaps, a more determined strategy aimed at self-preservation requires an understanding
and empathy that are best found in an experienced practitioner. Here, there is a valid role for the CMHN to work towards a meaningful therapeutic relationship, based on principles of interdependence, through which the person with dementia can be supported to make a decision on the place, and meaning, of day care in their lives.

Discussion

People with dementia are entitled to live as ‘normal a life as possible’ for as long as is possible and one of the primary aims of health and social care services should be to provide the means to make this happen. Sadly, over the past decade, the services afforded by either health or social care providers have become unbalanced (Department of Health 2001). Health aspects have become fairly well developed in respect of assessment, diagnosis and medical treatment, while social care support aimed at promoting satisfactory community living has been overwhelmed, in some cases reduced to the rudimentary, and in some cases, such as intermediate care, may be almost lacking.

The current situation represents a struggle for people with dementia to live productively in a place of their choosing within the community, and the reality is that they have frequently been disadvantaged by the lack of specific and dedicated support.

As mentioned earlier, just a little help to many people in need is of enormous significance to either people with dementia who live alone, or to family carers who are encountering difficulty of some description. Unfortunately, the ‘little help’ is disappearing as a service option as the eligibility thresholds for social care are constantly raised due to resource pressures (Godfrey et al. 2004). Many people remain isolated, and living at home, alone, with no support may be as disempowering and unstimulating as admission into the most depressing of care facilities.

However, a new paradigm may be emerging. Its roots are encapsulated within the ‘From welfare to well-being’ report (Joseph Rowntree Foundation 2003) which is published with one eye on the future demographic challenges facing the UK, while seizing an opportunity to promote ‘positive ideals’ for community support provision. The report makes a number of key recommendations (see Box 1.3) raising philosophical themes that are as applicable to people with dementia as they are to older people generally. There is a reflection of the value placed on the individual and an acknowledgement of the aspirations older people have to retain independence, choice and control. Throughout there is a theme that making efforts to engage more effectively with older people, or those who use support services, has been the most significant catalyst in changing policy.

Change in policy is evidenced by a growing desire being placed upon the movement away from a traditional focus upon ill-health and the frail elderly towards preventive strategies. In the context of dementia care, this move is therefore away from a focus predominantly upon services that respond to those people with severe symptoms or carers in crisis. This is to be welcomed as an opportunity to see a real departure from the traditional, often nihilistic, model that has promoted late referral and response and is at odds with the ethos of the National Service Framework for Older People (Department of Health 2001), as it applies to England.

We seem to be on the verge of a new and positive policy agenda which is influenced by quality of life, well-being, anti-ageism, equality, social inclusion, empowerment and valuing the individual. It represents a seismic change that has led to a debate about how best to
commission, provide and deliver services, which not only reflect these ideals, but also identify and address barriers to change. The Association of Directors of Social Services and Local Government Association (ADSS and LGA 2003) suggest that preventive strategies are the key to realizing a new landscape of community care provision. They are critical of the traditional model and propose an alternative (Figure 1.2), and argue that:

Future services need to reverse the trend by inverting the triangle so that the community strategy and promotion of well-being is at the top of the triangle and the extension of universal services for all older people is seen as crucial to all agencies.

(ADSS and LGA 2003)

The recent White Paper, *Our Health, Our Care, Our Say* (DH 2006) has begun to articulate how we might realistically invert the triangle of care. Through the Partnerships for Older People Projects (POPPS) (Care Services Improvement Partnership 2006), local authorities are starting to test mechanisms that will act to shift resources across whole systems, thereby encouraging preventive strategies to flourish. The aim is to move away from the current ‘patchwork’, characterized by inconsistent, incoherent and uncoordinated services with unstable resources, towards a ‘network’ of services with consistency in commissioning and funding. Under POPPS, many services, including those aimed at low-level need and prevention, will be commissioned and evaluated and there appears to be a built-in preparedness to learn from mistakes.

Overall, while investing in the prevention of illness and crisis is suggested as cost neutral, the philosophy involves a better use of resources and public services working together more effectively (ADSS and LGA 2003), it is also suggested that in judging value the emphasis moves away from quantifiable reductions in expenditure towards improve-

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<th>Box 1.3 Key recommendations of the Joseph Rowntree Foundation report, ‘From welfare to well-being’</th>
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<td><strong>Vision and culture:</strong> a new vision and culture are required to celebrate old age and recognize the value of older people in society, both individually and as a whole.</td>
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<td><strong>Ageism and discrimination:</strong> a stronger legal framework is required, based on age equality and a rights-based approach.</td>
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<td><strong>Poverty and income in retirement:</strong> a comprehensive review and reform are needed both legally and financially to address income in retirement and poverty.</td>
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<td><strong>Information and resources for choice and control:</strong> improvements are needed to enable older people to have greater choice and control particularly at times of transition.</td>
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<td><strong>Meeting the market needs of older people as consumers:</strong> need to address the failure of the market to meet demands for products and services that older people want to retain independence, choice and control.</td>
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<td><strong>Quality of life and well-being:</strong> action is needed to promote a quality of life and well-being approach.</td>
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<td><strong>Housing and support options:</strong> a broader set of options is required to support independence in old age.</td>
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<td><strong>Strategy, resourcing and commissioning:</strong> a stronger and more comprehensive framework is required.</td>
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ments in quality of life and independent living, as perceived by older people themselves. If these are to be the new standards by which we measure services, then it becomes evident that preventive strategies should aim to promote quality of life and not simply focus upon the prevention of admission to hospital or institution. At the local level the involvement of the CMHN may be fundamental to the overall success of this strategy.

The Chief Nursing Officer for England and Wales recognizes the valuable contribution that all community nurses play in supporting people with long-term conditions (Department of Health 2005a). In doing so, she draws attention to concerns about those with complex needs who experience uncoordinated care and frequent unplanned crisis interventions or admissions. We have earlier identified such problems as being characteristic of the traditional model of community support provision and agree with her statement that these people are not effectively supported and their ability to remain at home is compromised. They receive care that is intermittent, ad hoc, and reactive to crisis and has little relation to preventive strategies. Although many professionals and specialists may be involved, no one assumes overall responsibility for ensuring that all health and social care needs are met.

A framework for impacting upon this is offered (Department of Health 2005b), and while its emphasis upon the 20–30 per cent of people in greatest need continues to reflect the traditional model, it does also focus much upon the value of preventive interventions. The apex of the model is concerned with two groups; those who have complex needs (level three) and those who are highly at risk of developing complex needs (level two). Considering this model a little further allows us an opportunity to reflect on the role of the CMHN as a specialist involved in community support and preventive intervention.

Those people with dementia falling into the level two category (at risk of developing complex needs) will be those who require better disease management to promote their well-being and reduce their risk of deterioration. The CMHN probably works most frequently...
at this level of specialist intervention and both editions of this book are a testament to the
diverse array of possibilities that exist for the CMHN to preserve the integrity of people
with dementia and their families and promote optimum levels of health. In addition, level
two is characterized by nurses from different backgrounds working closely together to meet
needs by implementing protocols to protect vulnerable adults from abuse (see Chapter 12
by Simon T. O’Donovan) or for non-medical prescribing of medications to people with
dementia (see Chapter 9 by Sean Page). Overall, there is an emphasis at level two on
developing a comprehensive care plan with the active involvement of both the person with
dementia and their family networks, or supporters. This places us squarely within a triadic
approach to CMHN practice, an ideal in which all three parties (person with dementia,
their family/support network and the CMHN) act as a partnership with equality in com-
munication and decision-making, assuring that none of the parties becomes marginalized
(Fortinsky 2001). See also Chapter 7 in this book by Trevor Adams and Paula Gardiner.

In moving into level three (those with complex needs), the situation changes
considerably, as does the degree of complexity and risk; here we may well see more people
with dementia falling into this category as demographic changes (more females in the
workforce, more lone parents, more single people choosing to live alone, increased family
mobility and less traditional marital relationships, allied to a reluctance to take on (future)
caring responsibilities) impact upon society’s dependence upon the family to provide the
bulk of community care. Indeed, those at level three present with more severe illness,
polypharmacy, limitations to activities of daily living and several coexisting medical
conditions. As an example, it is not uncommon for a person with Alzheimer’s disease
to also have other medical complaints, such as cardiovascular disease, diabetes, and so
on. This emphasis moves towards effective case management within which all care
needs (health and social) are identified and met in an integrated way by skilled and
knowledgeable practitioners.

For some time now in the United Kingdom case management has been regarded as
central to government policy for the management of people with long-term conditions
who, with specialist and intensive support, are able to remain at home longer and have
increased choice on health and social care options (Department of Health 2005a). The case
manager is seen as being both the provider and procurer of care and assumes responsibility
for ensuring that all needs are identified and met. The underpinning principles of case
management are set out in Box 1.4 and a number of advantages have been identified.

<table>
<thead>
<tr>
<th>Box 1.4 Principles of case management</th>
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<tr>
<td>• Provide least invasive care in least invasive setting.</td>
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<tr>
<td>• Support effective primary care.</td>
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<tr>
<td>• Focus on patients in the community carrying the highest burdens of disease.</td>
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<tr>
<td>• Build partnerships with hospital care clinicians and social services.</td>
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<tr>
<td>• Identify patients who are at high risk of unplanned hospital admission.</td>
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</tbody>
</table>
| • Enable each patient to have a personalized care plan based on his or her needs,
preferences and choices. |
| • Integrate the patient journey throughout all parts of the health and social care system. |
Among these advantages are: the identification of those people in the community who have complex needs; the development of a multi-faceted care plan to meet those needs, an overall emphasis on preventive strategies; and an opportunity for patients and carers to make future plans and to exercise choice over the range of possibilities.

The role of ‘Community Matron’ is proposed as a means of delivering effective case management and is defined as being very much a nursing role for those with high-level skills in assessment, medicines management, negotiation, decision-making, resource allocation and enabling or empowerment of patients (DOH 2005a). While nurses with a district nursing background will fill the majority of roles, there is no barrier on mental health nurses also doing so, indeed, it is even suggested as a means of developing the Care Programme Approach for older people (DOH 2005a). It is, however, a requirement that all Community Matrons are sited within primary care and, although this does raise questions about the efficacy of primary care involvement with dementia care, it opens up a new possibility for the CMHN to be more closely aligned to GP practices and, additionally, to become more involved in early and ongoing intervention work.

**Summary**

If, as intimated earlier, community care has become ‘big business’, then it is a business that struggles with the reality that demand will always exceed supply; consequently, the traditional model of community support often fails to meet the needs and expectations of its customers. Available resources are targeted towards the most vulnerable while preventive strategies for those in less need are inadequately provided for. What this achieves is a perpetuation of an inherently flawed model as the risk of vulnerability is neither addressed nor reduced, and we are forced to conclude that many people with dementia are condemned to move towards a point of crisis and, ultimately, into continuing care without access to the choice, equality and autonomy of will that are becoming central to public policy and legislation (see Department of Health 2005a, 2005b).

Despite the laudable efforts of many who provide community care and support services, we have to acknowledge that the traditional system is inadequate. We are also minded to acknowledge that there are early signs of a new paradigm, focused on recovery, crisis prevention and the promotion of well-being, which is offered for discussion. The concern has to be that changing community care is such a mammoth task that any debate finds itself stuck at a stage of evangelical rhetoric with no movement occurring. To counter this, change must be evolutionary, rather than revolutionary, and we are seeing this pragmatic approach emerging from the Department of Health with an emphasis being placed on preventive strategies (Department of Health 2005b) and on the contribution that nurses and nursing can make to meet the needs of the most vulnerable while reducing future crisis for others (Department of Health 2005a).

Whatever the future may hold, it seems evident that the CMHN is conceptually and practically well placed to play a significant role in the provision of community care and support, whether this be under the traditional model or a radically different inverted pyramid model or perhaps, more realistically, in the transition between the two.
Lessons for CMHN practice

- People with dementia are entitled to live as ‘normal a life as possible’ for as long as is possible and a fundamental aim of health, social care and voluntary systems should be to provide the mechanisms to make this happen.
- People with dementia and their families are currently disadvantaged by a lack of dedicated and specific support.
- Implementing preventative strategies in the community to ‘ward off’ crisis points is a positive and necessary re-orientation of service values and support.
- The CMHN has an active and positive role to play in promoting quality of life for all people with dementia who are living in the community.

References


Page, S. (2003) From screening to intervention: the community mental health nurse in a memory...
Models of community support and practice values