

**NATIONAL COUNCIL FOR HOSPICE AND
SPECIALIST PALLIATIVE CARE SERVICES
AND
SCOTTISH PARTNERSHIP AGENCY FOR
PALLIATIVE AND CANCER CARE**

Positive Partnerships

**Palliative Care for Adults with
Severe Mental Health Problems**

Council and the SPA would like to record their thanks to the original steering group and researcher. The steering group facilitated the work of Nicholas Clarke whose report formed the basis of the work which Dr Julia Addington-Hall was commissioned to take forward in this report, "Positive Partnerships".

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Council and the SPA record their thanks to the **National Lottery Charities Board** for its support of the work of the original steering group and researcher and for enabling this report to be commissioned and written.

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Positive Partnerships

Palliative Care for Adults with Severe Mental Health Problems

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May 2000

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EXECUTIVE SUMMARY

‘Terminally ill patients with severe mental illness have as much right as anyone else to have their physical symptoms relieved and to receive appropriate psychological and spiritual support’

‘GPs should be seen as the ‘bridge’ between palliative care and mental health services’

- 1 This report addresses the palliative care needs of adults with pre-existing severe mental health problems who develop a life-threatening illness and require palliative care, and those of adults with dementia.
- 2 The aims of the report are to raise awareness in both the palliative care and mental health arenas of the needs of these patients, to facilitate discussion and partnership between the different agencies involved, to provide guidance about the way forward, and to highlight priorities for research.

The report is aimed particularly at providers and commissioners of hospices and specialist palliative care services, and those of specialist mental health services (including health and social services). It will also be of interest to service-users and voluntary organisations.

- 3 People with severe mental illness require skilled professional care from health and social care professionals with expertise in their management. The focus on their mental health problems can lead to the under-diagnosis of life-threatening illnesses and to the under-recognition and under-treatment of symptoms. They may receive fragmented care, with responsibility for their physical health passed across agencies. This is particularly likely when GPs are not involved in their care.

How much hospices and specialist palliative care services are involved in the care of people with severe mental illnesses is not known. Barriers to their involvement include a lack of appropriate skills to work effectively and safely with people with these illnesses, negative attitudes and prejudice and, on occasion, disagreement between these services and mental health services on the goals of care

Terminally ill patients with severe mental illness have as much right as anyone else to have their physical symptoms relieved and to receive appropriate psychological and spiritual support. Their families too have the same rights as other families for support both in the terminal phase and in bereavement. Professional carers, who may have been involved in supporting the patient for many years also need support, as do fellow-patients and friends.

GPs already have formal responsibility for the physical health needs of people with severe mental illness and increasing numbers are involved in their continuing support in the community. GPs also provide palliative care. They should, therefore, be seen both as the ‘bridge’ between palliative care and mental health services, and as the key provider of palliative care to patients with severe mental illness living in the community.

Partnership between mental health services, hospice and palliative care services and the primary care team is essential. Hospices and palliative care services should normally aim to enable the patient’s usual carers to provide good palliative care, rather than directly providing care themselves. Sometimes, however, it will be appropriate to care directly for patients and families.

The number of patients with severe mental illness who die each year is relatively small, and any one hospice or palliative care service is likely to have only rare referrals for these patients. It is unrealistic to expect them to be fully conversant in the management of these patients. They should however all ensure that their staff are familiar with the basics of management and know how to access emergency help. Negative attitudes should also be challenged. This is particularly important in inner cities, where the incidence of severe mental illness is highest.

- 4 Dementia can legitimately be seen as a terminal illness. Its prevalence increases with age. The AIDS-dementia complex is an important cause of dementia in younger people. New variant CJD may also become a significant cause of dementia in younger people in the future. Patients with end-stage dementia often have unmet palliative care needs for symptom relief and for support for their informal carers.

Hospices and specialist palliative care services largely lack expert skills in the behavioural and psychiatric management of patients with dementia, and caring for these patients alongside other patients can be problematic. They are not therefore an alternative to appropriate care in nursing homes, continuing care wards, or at home from psycho-geriatric services and from others specialising in the care of these patients. However, although these services can provide excellent end-of-life care this is not always the case.

Some hospices and specialist palliative care services may on occasion become directly involved in the care of the patient with end-stage dementia where there are particularly complex palliative care needs and when the prognosis is fairly certain.

However, their major role will be to work with health and social service professionals currently providing care for these patients, to support them during the terminal phase continuing into bereavement if appropriate, to educate them in the palliative care approach and to help them implement it in their care setting.

- 5 Priorities for research and development include an urgent need to investigate the views of users and potential users as to appropriate palliative care provision in severe mental illness and dementia; to improve assessment of pain and other symptoms in demented patients; the development of guidelines for treatment of pain in patients with severe mental illness; development and evaluation of joint training schemes for palliative care and care of the elderly health professionals; and research into the organisation and delivery of palliative care support and services to nursing and residential homes and to NHS continuing care units to improve end-of-life care.

'hospices and specialist palliative care services' major role will be to work with health and social service professionals currently providing care for these patients'

RECOMMENDATIONS

- 1 A continuing educational programme in the principles of palliative care for GPs must be available locally to enable all GPs to provide high quality palliative care for patients with life-threatening illnesses, including those with severe mental illness.
- 2 Many adults with severe mental illness die in acute hospitals, as do many patients with dementia. Continued efforts are needed to improve the quality of care for the dying in acute hospitals. Hospital palliative care support teams are likely to play a key role.

Severe mental illness

‘All hospices and specialist palliative care services should include in their education programme for staff and volunteers sessions challenging underlying attitudes to people with severe mental illness, and equipping personnel with basic skills in managing these people.’

- 3 All hospices and palliative care services should ensure that staff:
 - ❖ are familiar with the major mental illnesses, how these present, the signs of deteriorating mental state, and the basics of management.
 - ❖ are aware of the needs of these patients at the end of life, and the need to work in close partnership with mental health and social services
 - ❖ know how to access mental health services in emergencies.
- 4 All hospices and specialist palliative care services should include in their education programme for staff and volunteers sessions challenging underlying attitudes to people with severe mental illness, and equipping personnel with basic skills in managing these people.
- 5 Services in inner city areas, where the incidence of severe mental illness is highest, should:
 - ❖ Designate a link nurse/doctor with the responsibility for developing and maintaining links with local mental health and social services.
 - ❖ Work with these services to develop protocols to ensure the safety of staff, visitors and other patients – and the patients themselves.
 - ❖ Establish educational awareness programmes for staff and volunteers as a matter of urgency.
 - ❖ Consider the appointment of a resident mental health nurse, and ensure that the service has regular and agreed access to liaison psychiatry.
 - ❖ Identify skilled interpreters to improve the accuracy of assessment of mental health needs of those who do not speak English as a first language.
- 6 All long-stay psychiatric units and the high security hospitals should appoint palliative care link nurses to ensure patients who die from cancer and other life-threatening illnesses in these units receive high quality palliative care. Their responsibilities should include to:
 - ❖ establish and maintain links with local hospice and specialist palliative care services.

- ❖ establish and maintain resource files
- ❖ ensure the availability of special equipment such as syringe drivers, and
- ❖ educate other health professionals in their use.

These recommendations also apply to prisons.

- 7 Health and social services should recognise that staff who have provided care over long periods to individuals with severe mental illness need support in the face of terminal illness and in bereavement. The impact on fellow patients also needs to be recognised. Research into these needs and the best ways of meeting them is needed.

Dementia

‘Initiatives ... aimed at improving care for the dying in nursing homes should be evaluated and the results widely disseminated’

- 8 GPs should be educated in the palliative care approach in enable them to be confident both in providing high quality palliative care for their patients, and in making appropriate referrals to hospices and to specialist palliative care services. This is particularly important in view of the role of GPs in providing medical cover for nursing and residential homes.
- 9 Initiatives across England and Wales and Scotland aimed at improving care for the dying in nursing homes should be evaluated and the results widely disseminated. More such initiatives are needed. In particular,
 - ❖ Local hospices and specialist palliative care services should work with local nursing homes to provide appropriate and high quality education in the palliative care approach to nursing home staff.
 - ❖ Nursing homes should designate link nurses with responsibility for maintaining links with local hospices and specialist palliative care services, for increasing their own palliative care skills and cascading knowledge back to other nursing home staff, and for maintaining resource files.
 - ❖ The support needs of nursing home staff who may have cared for individuals for lengthy periods should also be considered.
 - ❖ Hospices and specialist palliative care services should consider the appointment of specialist palliative care nurses specifically for residents of nursing homes.
- 10 NHS continuing care units and psychogeriatric wards should consider similar initiatives.
- 11 Local care of the elderly and palliative care services should develop joint training programmes for palliative care, nursing home and care of the elderly staff.
- 12 Close collaboration between psycho-geriatricians and palliative care specialists is needed to ensure all patients receive high quality end-of-life care regardless of cognitive status.
- 13 Protocols need to be developed to ensure that individuals admitted to acute hospitals in the end stages of dementia do not receive aggressive, life-sustaining treatments inappropriately. Hospital palliative care support teams have an important role to play in their development, and in helping clinical teams make end-of-life decisions.

‘Hospices and specialist palliative care services should challenge attitudes of staff to older people and ensure care is provided on the basis of need, not age’

- 14 Hospices and specialist palliative care services should challenge through education programmes the attitudes of staff to older people and ensure care is provided on the basis of need, not age.
- 15 Hospices and specialist palliative care services should be aware of the likely increase in demand for inpatient care for younger patients with AIDS related dementia and CJD and should be considering, in conjunction with local health commissioners and other services, what role they would envisage taking in the care of these patients.

INTRODUCTION

‘There is growing evidence that anxiety and depression are under-detected and under-treated in palliative care patients’

- 1 This report addresses the palliative care needs of two groups:
 - i Adults with pre-existing severe mental health problems who develop a life-threatening illness and require palliative care
 - ii Adults with dementia
- 2 The needs of adults with learning disabilities are not considered here.
- 3 The challenges presented to hospices and specialist palliative care services by patients who develop severe mental health problems whilst receiving palliative care are not addressed here. However, many of the recommendations about how these services should address the needs of patients with pre-existing severe mental illness can also be applied in this situation.
- 4 Many palliative care patients experience periods of anxiety and depression, and in a significant minority symptoms are sufficiently severe to warrant diagnosis of clinical depression/anxiety. There is growing evidence that anxiety and depression are under-detected and under-treated in palliative care patients.^{1,2} This is an important issue for palliative care services, not least because of the distress these symptoms cause patients and families. They are not, however, covered in this report.
- 5 Delirium and confusion are also common symptoms in palliative care patients. In some patients these are irreversible, but in others careful assessments will identify reversible causes of delirium.^{1,3} The needs of, and appropriate service provision for, palliative care patients who experience delirium and confusion at the end of life are not included in this report.
- 6 This report was commissioned by the NCHSPC/SPA to follow on from their report ‘*Reaching Out*’,⁴ which examined the palliative care needs of patients dying from progressive non-malignant diseases and those of patients living with chronic non-malignant disease. ‘*Reaching Out*’ explicitly did not address dementia, nor did it consider the particular issues raised in caring for people with severe mental illness. This report was therefore commissioned to provide guidance on addressing the palliative care needs of these two patient groups. It will be used by the NCHSPCS and the SPA to facilitate joint training between palliative care and mental health professionals, in partnership with mental health organisations.
- 7 In writing the report the author drew, amongst other sources, upon the deliberations of the NCHSPCS/SPA Working Party on Palliative Care for Adults with Mental Health Problems, and on the results of the qualitative needs assessment undertaken for the Working Party.*

* Clarke N. Palliative Care for adults with mental health problems: a qualitative needs assessment. Unpublished report.

- 8 The report is informed by the views of health and social care professionals consulted by the Working Party and subsequently by the author, by the views of professional bodies and voluntary organisations who commented on earlier drafts of the report, and by an extensive literature review. The views of users – or potential users – of palliative care services and/or specialist mental health services are therefore under-represented. Canvassing the views of service users and working with them to shape appropriate services is an important early priority for future research.
- 9 This report is predicated primarily (but not exclusively) on the English position as regards the organisation and delivery of health and social care. However, the key messages are common to the UK as a whole.

DEFINITIONS

1. Palliative Care

The NHS Executive in EL(96)85⁵ defines the palliative care approach, palliative interventions and specialist palliative care as the principal components of the spectrum of palliative care provision. These definitions follow closely those contained in the NCHSPCS' Occasional Paper 8⁶ *Specialist Palliative Care: A Statement of Definitions*, and those laid out in the Scottish Cancer Co-ordinating and Advisory Committee report on Primary and Palliative Care Services.⁷

The palliative care approach aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles and supported by specialist palliative care. The key principles underpinning palliative care which should be practiced by all health professionals in primary care, hospital and other settings comprise:

- ❖ Focus on quality of life which includes good symptom control
- ❖ Whole-person approach taking into account the person's past life experience and current situation
- ❖ Care which encompasses both the person with the life-threatening disease and those that matter to the person
- ❖ Respect for patient autonomy and choice (eg over place of care, treatment options, access to specialist palliative care)
- ❖ Emphasis on open and sensitive communication, which extends to patients, informal carers and professional colleagues

Palliative interventions are non-curative treatments given by specialists in disciplines other than specialist palliative care aimed at controlling symptoms and improving a patient's quality of life, for example through the use of palliative radiotherapy, chemotherapy, surgical procedures and anaesthetic techniques for pain relief.

Specialist palliative care services are those services with palliative care as their core speciality. Specialist palliative care services are needed by a significant minority of people whose deaths are anticipated, and may be provided directly through specialist services, or indirectly through advice to a patient's present professional advisers/carers. These services provide physical, psychological, social and spiritual support, and will involve practitioners with a broad mix of skills, including medical and nursing, social work, pastoral/spiritual care, physiotherapy, occupational therapy, pharmacy and related specialities.

2. Severe mental illness

Following the definitions adopted by the Framework for Mental Health Services in Scotland⁸ and by the Working Group for the NHS National Service Framework for Mental Health,⁹ severe mental illness is taken in this report to mean individuals who:

- ❖ have a mental health disorder as designated by a mental health professional
- ❖ experience a substantial disability as a result of their mental health problems, such as an inability to care for themselves independently, sustain relationships or work
- ❖ require formal or informal care
- ❖ are either currently displaying obvious and severe symptoms, or have a remitting/relapsing condition
- ❖ have experienced recurring crisis leading to frequent admission/intervention
- ❖ occasion significant risk to their own safety (via unintentional self-harm, intentional self harm or abuse by others) or that of others.

Diagnoses include schizophrenia, bipolar affective disorder, recurrent depressive disorder, organic mental disorder, severe anxiety disorders and severe eating disorders.

3. Dementia

In this report, we are concerned primarily with irreversible dementia, characterised by progressive deterioration of intellect, memory and personality. The most common cause is Alzheimer's disease, followed by 'multi-infarct' or vascular dementias. It may, however, result from other progressive diseases such as Huntington's disease and Parkinson's disease. The particular issues raised by new variant CJD, and by the AIDS dementia complex are mentioned, but not discussed in detail.

AIMS OF REPORT

This report aims to improve the palliative care received by people with severe mental illness or dementia by:

- ❖ raising awareness in both the palliative care and mental health arenas of these patients' needs.
- ❖ facilitating discussion and partnership between the different agencies involved.
- ❖ providing guidance about the way forward.
- ❖ highlighting priorities for research.

It will be of particular interest to providers and commissioners of:

- ❖ hospices and specialist palliative care services
- ❖ specialist mental health services, including health and social services

It will also be of interest to service-users and voluntary organisations.

SEVERE MENTAL ILLNESS

‘Most people with severe mental illness die from the same causes as the rest of the population: having severe mental illness does not protect against diseases such as heart failure, COPD, or most cancers’

1 This section of the report focuses on people with severe, enduring or recurrent mental health problems. This definition encompasses people with schizophrenia, bipolar affective disorders, recurrent depressive disorder, organic mental disorders, severe anxiety disorders and severe eating disorders. These people have complex needs which may require continuing care from mental health services, social services and housing, as well as the primary care team. Most manage well with this care, and many live with their families. The prevalence of severe mental illness is estimated to be in the region of 1 to 2 per cent of the adult population.^{8,9}

2 Services for people with severe mental illness

People with severe mental illness require skilled care from professionals who have, for example, expertise in maintaining patients on appropriate medication, in knowing how to anticipate and prevent crises, and in crisis interventions. Specialist mental health and social services in the community include community mental health teams, local residential care, day care, and domiciliary support.

Despite the move to community care over the past three decades, inpatient care remains important, particularly in Scotland.⁸ Most admissions are however short-term in local acute mental health units. Others admissions are to medium and high secure units and to high security hospitals.

Many people with severe mental illness are in contact with their local mental health services. However, it is estimated that in the past around half of those with severe mental illness were discharged from or lost contact with these services, leaving their GP to provide continuing care.¹⁰ Greater efforts are now being made to stay in touch, especially if people are perceived to be a risk to themselves or others. Evidence from a recent study suggests a much higher percentage (84%) now remain in contact with mental health services five years after an episode of psychotic illness.¹¹

3 Causes of death

People with severe mental illness are at increased risk of suicide or violent death. For example, people with schizophrenia have significantly increased mortality from suicide, and from accidents.¹² However, schizophrenia is also associated with a moderate increased mortality from natural causes¹³. Most people with severe mental illness die from the same causes as the rest of the population: having severe mental illness does not protect against diseases such as heart failure, COPD, or most cancers¹³ (although the rate of lung cancer is lower than would be expected in men with schizophrenia¹²). Given high levels of smoking and drinking, some life-threatening diseases (such as COPD and liver failure) are likely to be more common in people with severe mental illness than in the population as a whole.

3 Physical health care

At the end of life, as throughout the ‘career’ of a person with severe mental illness, there is a danger that their physical needs are overlooked. The focus on mental health problems can lead to the under-diagnosis of life-threatening

‘Patients may sometimes have difficulty getting their physical symptoms taken seriously’

illnesses, and to the under-recognition and under-treatment of symptoms. Patients may sometimes have difficulty getting their physical symptoms taken seriously.

There is a real danger that patients receive fragmented care, with responsibility for their physical health passed across agencies. The National Service Framework in England for Mental Health⁹ argues that the mental health services assessments⁷ of people with severe mental illness should also cover physical health needs, especially given evidence of high levels of physical ill-health and high death rates amongst those with mental health problems compared to the rest of the population;^{13,14} responsibility for the physical care of these patients, although formally held by the GP, needs to be explicitly allocated and accepted.

Fragmented care and lack of attention to patients’ physical well-being is particularly likely when GPs are not involved on a day-to-day basis in the care of these patients. The Framework for Mental Health Services in Scotland⁸ stresses the need to integrate primary care with secondary health and social care for people with severe mental illness. In recent years some GPs have become more fully involved in providing continuing support for people with severe mental illness and this is likely to provide more opportunity for their physical – as well as their mental health – needs to be assessed and managed appropriately.^{15,16}

5 Palliative care

Little has been published on the palliative care needs of people with severe mental illness.¹⁷ This reflects the focus on their mental health needs. It may also reflect a reluctance on the part of hospice and specialist palliative care services to care for these patients. Although empirical evidence is lacking, many people with severe mental illness who develop cancer or other life-threatening illnesses probably have insufficient attention paid to their palliative care needs.

6 Barriers to palliative care involvement

There is no data on the extent to which hospices and specialist palliative care services in the United Kingdom are currently involved in the care of people with severe mental illness. There are however a number of barriers to their involvement:

- 6.1 People with severe mental illness require expert care to manage their medication, to prevent crises, and to provide appropriate care at times of crisis. Such help comes primarily from specialist mental health and social services, although increasingly the primary health care team (including GPs, practice and community nurses) takes on at least part of this role. Most hospices and specialist palliative care services understandably feel that they lack the skills to work effectively and safely with people with severe mental illness. Palliative care specialists are right to recognise the limits of their expertise. However, knowledge and skills can be acquired, and a lack of expertise can not, therefore, justify a continuing reluctance to provide palliative care for these patients.
- 6.2 Health professionals working in hospices and specialist palliative care may hold the same negative attitudes towards people with severe mental illness as other members of society. Survey results indicate that people feel strongly about mental illness: most people are genuinely

‘many people with severe mental illness who develop cancer or other life-threatening illnesses probably have insufficient attention paid to their palliative care needs’

‘Reluctance to develop skills in the care of people with severe mental illness may, therefore, result from prejudice’

caring and sympathetic but they are also concerned about the danger which they associate with a very small number of people with severe mental illness.^{18,19,20} Negative media coverage of mental health is widespread.²⁰ Both the Framework for Mental Health Services in Scotland⁸ and the NHS Executive’s National Service Framework for Mental Health⁹ argue that public education is urgently needed to reduce the stigma attached to mental illness. Reluctance to develop skills in the care of people with severe mental illness may, therefore, result from prejudice.

- 6.3 A further barrier to hospice and specialist palliative care services providing palliative care for people with severe mental illness is that psychiatric services may disagree with palliative care services on the goals of care. This is exemplified by the debate on the appropriateness of a hospice in England providing terminal care for a patient with anorexia nervosa.²¹ Psychiatrists with expertise in the care of these patients seemed shocked that efforts to sustain life in this patient had been abandoned, as their experience showed that many (although not all) such patients would eventually recover.²² They were concerned that health professionals without experience in anorexia nervosa might be over-influenced by the patient’s own sense of hopelessness and thus come to believe nothing more could be done. Although there is no evidence that this was the case in this situation, it does demonstrate the danger that health professionals who lack expertise in the care of a specific mental illness may inappropriately decide that the patient’s distress means that the goal of care should change from curative to palliative. However, there is a parallel danger – perhaps more likely in practice – that specialists in mental health will miss signs and symptoms indicating that the patient now has an advanced physical disease and that palliative care is therefore needed to prevent distress.

7 How might palliative care be improved?

Given these barriers, and the understandable focus of mental health services on mental health problems, how can palliative care be improved for people with severe mental illness who are at the end of their life and/or have distressing symptoms which would benefit from palliative care interventions.

- 7.1 It is important to recognise that people with severe mental health problems who have life-threatening illnesses will have the same physical symptoms as other patients with the same pathologies. In addition, coming to terms with the end of one’s life may be particularly difficult when this has been punctuated or characterised by severe mental illness and, particularly for the older generation who have spent perhaps many years within long-stay psychiatric hospitals, without the opportunity to experience aspects of life taken for granted by others.

People with severe mental illness have as much right as anyone else to have physical symptoms relieved and to receive appropriate psychological and spiritual support as they approach the end of their life.

Their families too have the same right as other families to support both in the terminal phase and in bereavement. In addition, the patient’s illness and death can be distressing both for workers from mental health or social services who may have supported the patient for many

‘People with severe mental illness have as much right as anyone else to have physical symptoms relieved and to receive appropriate psychological and spiritual support as they approach the end of their life’

‘Partnership with mental health services (including health, social and housing agencies) and the primary health care team is essential’

years, and for fellow patients in psychiatric in-patient units, residents in homes in the community, and friends. They too may need support during the illness and in bereavement.

- 7.2 In many cases it will be appropriate for hospice and specialist palliative care services to enable the patients’ usual service providers to provide good palliative care, rather than directly providing care themselves. Direct patient care will however on occasion be important and appropriate.
- 7.3 Partnership with mental health services (including health, social and housing agencies) and the primary health care team is essential. Palliative care experts need to recognise their own lack of experience with severe mental illness, but also to act as advocates for patients at the end of life to ensure that their palliative care needs are recognised and met. They need to negotiate roles clearly to ensure that responsibility for these patients is not passed across agencies with the patient consequently ‘falling through the gap’.

Close partnerships will benefit the staff involved, as well as benefiting patients and families. Health and social care staff supporting people living with severe mental illness in the community can offer palliative care staff the information they need to be able to anticipate the patient’s likely response during the progression of the physical illness; they can assist staff training in confronting stereotypes; and they can provide support from other professionals who know the patient well. In return, support from palliative care colleagues will help statutory and voluntary staff providing care in the community to maintain the individual in their ordinary residence for as long as possible, provide support to family carers and to fellow residents in group-living situations, and ease the transition to inpatient care if needed.

Psychiatric liaison nurses may have a particularly important role to play in developing close partnerships between mental health and palliative care services. They are increasingly recognised as a means of organising collaborative work between mental health nurses and their colleagues in palliative care, community nursing services and specialist in-patient units. They can work directly with the patient and their family following a referral, or indirectly provides support through mental health consultation. Consultation may incorporate clinical advice and guidance, education, support and supervision. The responsibility for care remains with the referring nurse who may improve their knowledge and skill in managing mental health problems through the consultation process.

- 7.4 Partnership depends, however, upon health and social services already in contact with these patients referring them to hospices and specialist palliative care services. Whilst most palliative care specialists at least know of the existence of mental health services and may think of making a referral when appropriate, many mental health specialists are less informed about hospices and specialist palliative care services. The appointment of liaison psychiatrists, community psychiatric nurses and psychologists to hospices and specialist palliative care services on a sessional basis is an important way of bringing these services and mental health services together.

Working in close partnership when referrals are received will help to raise awareness amongst mental health specialists and (provided appropriate care is achieved) will increase referrals in the future. However, this will have an effect in the medium to long-term. The same would be true of efforts to raise awareness amongst mental health specialists by holding joint educational initiatives etc.

Box 1: A mental health specialist as part of the multi-disciplinary team in a hospice

Some hospices now have a liaison psychiatrist, community psychiatric nurse or psychologist as part of their multi-disciplinary team to address the mental health needs of patients using the services. In one hospice the psychiatrist provides one session a week and is fully integrated into the work of the team. They regularly attend team meetings to facilitate discussions about patients' mental health problems and treatment options, as well as providing advice as appropriate. This helps to relieve staff anxieties regarding the care of people with mental illness. Staff are now more familiar with mental health problems and interventions and are more able to provide care for people with mental health problems.

'GPs should therefore be seen both as the 'bridge' between hospices and specialist palliative care services and acute mental health services and as the key provider of palliative care to patients with severe mental illness who are living in the community'

- 7.5 GPs already have responsibility for the physical health needs of people with severe mental illness and increasing numbers are involved in the continuing support of these people in the community.^{16,17} GPs also provide palliative care for their patients and many already have good relationships with local hospices and specialist palliative care services. GPs should therefore be seen both as the 'bridge' between hospices and specialist palliative care services and acute mental health services and as the key provider of palliative care to patients with severe mental illness who are living in the community.

This places fresh emphasis on the need to ensure that all primary healthcare teams are able to provide good palliative care and know when to access specialist help and advice. There is ample evidence over the past thirty years that whilst some GPs provide excellent care this is not always the case.^{23,24,25} Further attempts to improve palliative care in primary care and to ensure appropriate referrals to hospices and specialist palliative care services from primary care will pay larger dividends in improving the palliative care provided for people with severe mental illness than focusing solely on improving awareness amongst mental health specialists.

- 7.6 The number of patients with severe mental illness who die each year from cancer or life-threatening illnesses is relatively small, and any one hospice or palliative care service is therefore likely to rarely have referrals for these patients. This will continue to be the case, even if the proportion of patients in need were referred to these services is increased. It is therefore unrealistic to expect all hospices and palliative care services to be fully conversant in the management of adults with severe mental illness.

‘all hospices and specialist palliative care services should have in place policies and procedures for accessing emergency advice if needed’

‘all hospices and specialist palliative care services should . . . be equipped to deal in a fair and appropriate manner with patients with severe mental health problems’

However, staff working in these services should be familiar with the major mental illnesses and, in particular, how these present, what signs to look for as evidence of deteriorating mental state, and the basics of management. This will help avoid emergency situations, as many problems can be anticipated.

- 7.7 In addition, all hospices and specialist palliative care services should have in place policies and procedures for accessing emergency advice if needed for patients, relatives, volunteers – or staff. Although this information will rarely be needed, the distress – and in extreme cases danger to the patients and others – that could result from delays in accessing emergency psychiatric support means that all services should have this information available.

This may be difficult in practice: in 1997 two-thirds of health authorities in England and Wales reported that they did not yet provide access to the community mental health team throughout the 24-hour period, 50% had no local helpline and 50% were unable to provide immediate support.⁹ However, both the Framework for Mental Health Services in Scotland⁸ and the National Service Framework for Mental Health⁹ place emphasis on assuring timely access to services and the provision of 24 hour, 7 days a week crisis response with access to appropriate community and in-patient facilities. The situation should, therefore, improve.

- 7.8 Given the widespread evidence of prejudice against people with severe mental illness, all hospices and specialist palliative care services should include in their education programme for staff and volunteers sessions which challenge these underlying attitudes. Although the number of patients referred to them with severe mental illness is likely to be small, they still need to be equipped to deal in a fair and appropriate manner with these patients, and with others with severe mental health problems who come into contact with the service as family members or visitors of other patients.

- 7.9 Severe mental health problems can result from (or be exacerbated by) a range of adverse factors associated with social exclusion. They can also be the cause of social exclusion: for example between a quarter and half of people using night shelters or sleeping rough may have a serious mental disorder; people with drug and alcohol problems have high rates of other mental health problems; and rate of schizophrenia are higher in urban than semi-rural or rural areas.⁹ Hospices and specialist palliative care services in inner-city and deprived areas should expect a higher prevalence of people with mental health problems amongst their patient group, and amongst families and friends of patients. These services should therefore consider:

- ❖ designating a link-nurse/doctor with the responsibility for developing and maintaining links with the local mental health services (including both health and social care agencies).
- ❖ working with local mental health services to develop protocols to ensure the safety of staff, visitors and other patients and the patients’ themselves.
- ❖ developing educational awareness programmes for staff and volunteers as a matter of urgency.

‘All long-stay psychiatric units and high security hospitals should appoint palliative care link-nurses to ensure that patients who die from cancer . . . receive high-quality palliative care’

- ❖ appointing a registered mental health nurse to the service. These nurses could take a similar role to psychiatric liaison nurses based in Accident and Emergency departments: to perform psychological and social needs assessments, provide knowledge of local services, and offer training and support to other staff.
 - ❖ identifying skilled interpreters to improve the accuracy of assessment of mental health needs for those who do not have English as their first language.
- 7.10 All long-stay psychiatric units and high security hospitals should appoint palliative care link-nurses to ensure that patients who die from cancer and other life-threatening illnesses receive high quality palliative care. Their responsibility should include:
- ❖ to establish and maintain links with local hospice and specialist palliative care services
 - ❖ to establish and maintain resource files
 - ❖ to ensure the availability of special equipment such as syringe drivers
 - ❖ and to educate other health professionals in their use.

Box 2: Employing registered mental nurse as part of the multi-disciplinary palliative care team

A local palliative care service has appointed a registered mental nurse as a core part of the team. A liaison psychiatrist provides one session a fortnight. The registered mental nurse provides some direct care to patients and families including: facilitating support groups, using cognitive behavioural approaches, and screening patients for anxiety and depression. She also provides advice, information and clinical supervision to other members of the multi-disciplinary team and plays an important liaison role with both community and in-patient psychiatric services.

DEMENTIA

- 1 This section is concerned with the palliative care needs of adults with dementia – a life-limiting illness which is in itself a severe mental health problem. People with dementia experience progressive loss of memory and higher intellectual function. They have difficulties in abstract thinking, planning, judgement and language and can show dis-inhibited behaviour, mood disturbances and personality changes. In the later stages, people with dementia are dependent on others for all aspects of care: they may be mute, bedridden, unable to feed or swallow. Alzheimer's disease is the most common cause of dementia, with multi-infarct dementia the next most common. People with Parkinson's Disease and Huntington's Disease may also become demented in the later stages of their illness.

The AIDS dementia complex is an important cause of dementia in younger people. Estimates of its prevalence in people with HIV/AIDS vary from less than 10% to nearly 40%.^{26,27} The number of people affected is likely to increase as the total numbers of people infected increase, and antiretroviral and other anti-infective therapies, notably triple therapy, improve patient survival. This increases the chances of a person living to develop HIV-related brain impairments. In addition, people may begin triple therapy once such impairments have been diagnosed and live with an extended life expectancy but with significant cognitive impairment. As these individuals are usually from younger age-groups they are often physically more robust than older people with dementia, which may result in an extended life-span. The social circumstances of at least some people with HIV/AIDS include issues such as asylum seeking, homelessness, drug and alcohol use which can make management and care particularly complex.

New variant CJD may also become a significant cause of dementia in younger people in the future.

2 Services for people with dementia

Individuals progress with dementia at different rates and with different symptoms. People with dementia consequently have varying care needs and may be cared for within a variety of settings. Many live at home, supported by husbands, wives and other informal carers. Others live in residential or nursing homes. In the past decade NHS provision within continuing care wards in NHS hospitals has diminished to be replaced by a rapid growth in nursing home provision. However, almost half the people with dementia in long-term care in Scotland are still cared for within hospital settings, including within old psychiatric hospitals, often in wards originally intended for young adults.²⁸ In England, and in lesser extent in Scotland, key medical responsibility for the care of many of these patients has shifted from geriatricians and psycho-geriatricians to GPs.

3 Dementia and cancer

The prevalence of dementia increases with age, from about 2% of people aged 65 to 70 affected compared to approximately 20% of people over the age of 80. The prevalence of cancer also increases with age. A proportion of

patients with dementia will also therefore have cancer. Cancer is likely to be diagnosed at a later stage in these patients than in patients able to communicate, particularly if there are a few visible signs such as weight loss and/or nausea, and the patient is unable to communicate their pain.²⁹

4 Palliative care for dementia patients in the USA

The unquestioning prolongation of life at all costs in at least some USA care settings has led to recognition of need for an alternative care system for dementia patients, one in which physicians are encouraged to recognise when curative treatment is inappropriate and when the morbidity associated with treatment outweighs the benefit: discomfort from invasive or painful procedures and prolongation of dying by life-sustaining treatment is argued to be a major cause of suffering at the end of life of these patients.^{30,31} Hospice programmes for end-stage dementia patients have therefore developed to a greater extent in the USA than in the UK. The Hospice Medicare Benefit has provided a financial motivation for hospice services becoming involved in the care of these patients. However, this benefit is only available for patients with a terminal prognosis of six months or less. The difficulty in making such a prognosis in dementia patients has led to concerns about taking on patients who may survive for longer. This is an understandable concern in light of the potential heavy penalties for services taking on patients who do not die within this time period. Consequently, despite the interest in providing hospice care for these patients very few USA patients receive this care. A national census survey for USA hospice programmes revealed very low rate of hospice utilisation, with dementia patients making up less than 1% of hospice patient.³² This has increased in recent years, but although the relevance of hospice care to these patients has been recognised this has not been matched to the same extent by service delivery. Nevertheless, the palliative care needs of dementia patients have to date received much more attention in the USA than in the UK where there has been little interest in developing hospice-type services for patients with dementia (an exception is the development by the Dementia Relief Trust of Admiral nurses, who provide a 'Macmillan'-type service for people affected by dementia).

5 Barriers to providing palliative care

A number of barriers to providing palliative care in the UK for patients with dementia can be identified:

- 5.1 Despite the progressive nature of dementia, it is not widely recognised as a terminal illness. Dementia is under-reported on death certificates in the UK by around 30 – 40%, with some studies suggesting that as many as two-thirds of people who die with dementia do not have dementia recorded on their death certificate.³³ Researchers in this field have concluded that 'as a cause and contributing cause of death, dementia is not so much overlooked as ignored'.³³ The rate of under-reporting of dementia on death certificates does not vary by place of death, indicating that both GPs and hospital doctors are unlikely to acknowledge dementia as a contributing cause of death.
- 5.2 Difficulties in judging prognosis for end-stage dementia patients are a barrier to these patients being cared for directly by hospices and specialist palliative care services. These services are targeted at patients with short life expectancy. They are concerned about taking on patients

'Despite the progressive nature of dementia, it is not widely recognised as a terminal illness'

who survive for longer periods as this restricts the number of patients who can receive their care. Although new methods of judging prognosis in dementia patients are being developed,³⁴ there is still considerable uncertainty. Not only is this a barrier to hospice and palliative care services being prepared to take on these patients but it is, of course, also a barrier to health professionals in primary and secondary care recognising the palliative care needs of these patients.

- 5.3 A further barrier to hospices and specialist palliative care services becoming involved in the care of people with dementia, is concern over the management of challenging behaviour for example, 'wandering'. Behavioural/psychiatric management rather than symptom management, may need to be the most prominent component of the care plan for these patients. This presents challenges for hospices: staff are not used to dealing with these sorts of behaviours, often lack the necessary skills, and are caring in an environment not specifically designed to be appropriate for demented patients. There is, therefore, often a general feeling that these patients cannot be appropriately cared for in inpatient hospices. However, although this may well be true, hospices are not unfamiliar with patients who are confused or have behavioural problems: many hospice inpatients develop delirium at some point in their admission, and patients with, for example, cerebral metastases present some of the same challenges as patients with dementia.
- 5.4 Patients with dementia may be perceived as less rewarding by hospice staff who are unable to use some of their expertise with these patients. One critical difference between patients who develop delirium during the course of their terminal illness is that patients with primary dementia are unlikely at any point in their contact with hospice services to be capable of knowing that they are dying and are therefore less amenable to the usual non-pharmaceutical strategies that hospice staff use. It has been noted elsewhere that hospice workers derive professional satisfaction from the emotional relationships developed with patients during the course of the terminal illness. This relationship may be quite different with a demented patient who is combative, unappreciative or simply unable to engage in the intimate dialogue that usually characterises hospice care.³⁵
- 5.5 A further barrier to hospices and specialist palliative care services becoming involved in the care of dementia patients is that the care of these patients may be seen as 'low status' compared with caring for younger cancer patients engaged in a heroic fight to live fully until death. Older people access hospice services in the UK and elsewhere in smaller proportions than younger patients with similar physical problems.³⁶ Research is underway to investigate whether this is a product of ageism on the part of the hospices and palliative care services, and/or on the part of referrers, and/or whether the patients themselves are less likely to want this care. In the meantime, the possibility remains that ageism may be one reason why hospices and specialist palliative care services are reluctant to care for demented patients.

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6 Palliative care needs in dementia

Having reviewed some of the reasons why hospices and specialist palliative care services in the UK are not in the main involved in the care of demented patients, this section considers the needs of these patients and families for palliative care. It is, of course, possible that the health professionals currently providing care for these patients are fully and appropriately meeting their palliative care needs.

- 6.1 However, there is growing evidence of poor pain and symptom control in people with dementia.³⁷ For example, a small UK study reviewing the casenotes of patients with end-stage dementia who died in a long-stay psychiatric ward found that pain and dyspnoea in particular were common and were not adequately palliated: all patients appear to be in some distress in the last 48 hours of life. Analgesia were prescribed to be administered on request, but were rarely in practice administered because the patients were unable to articulate their distress. The author concluded that symptoms were under-detected and under-treated.³⁷ Adequate pain and symptom control usually depends upon patients being able to communicate with health professionals, thus providing them with necessary information they need to provide appropriate palliation. The communication problems of people with dementia are therefore a real challenge to adequate palliation. Despite these difficulties already well-established basic principles of good symptom control need to be applied to these patients. Analgesics need to be prescribed to be administered regularly, for example, rather than on request.

One approach to assessment which may prove to be useful is to determine the symptom distress likely to be experienced by people with similar clinical problems, and to make treatment decisions based upon this, rather than from assessments (likely to be inaccurate) of the distress the patient is experiencing. For instance, Morrison et al³⁰ overcame difficulties in assessing the discomfort caused by procedures to demented patients by assessing the discomfort caused by these to non-demented patients and arguing that demented patients were likely to experience similar problems. A similar approach could therefore be adapted to pain and symptom control in demented patients. For example, where the demented patient is known or suspected to have lung cancer, then treatment could be provided on the basis of the pain lung cancer patients in general experience, rather on the basis solely of clues from the patients themselves.

- 6.2 In addition to the impact on patients with dementia themselves, families and informal carers of people with dementia experience considerable stress: studies which have compared the stress levels of informal carers of cancer patients to those of demented patients have found that the latter group experience more strain and are less likely to find caring rewarding. One reason for this is the unpredictable time period over which caring is required. Continuity of carers and familiarity of the environment are important for individuals with dementia, making it difficult for carers to access respite care, even when available. The need to come to terms with caring for a loved one who no longer recognises you and who has no memories of your shared past is another source of stress. There is growing recognition of the need to provide support for informal carers in the community. However, such

'there is growing evidence of poor pain and symptom control in people with dementia'

'basic principles of good symptom control need to be applied to these patients'

support is still difficult to access and not uniformly available across the country. Informal carers need expert help to deal with the behavioural and management problems of people with dementia, but they also need support for themselves in coming to terms with the loss of the person they knew.

Distress is not restricted, however, to informal carers: paid carers – whether in the patient’s own home, nursing homes or NHS continuing care wards – may have cared for the patient for a lengthy period and may also need support.

‘Palliative care services will, however, only be able to provide direct care to a small proportion of people living with dementia . . . health and social services currently providing care for people with dementia (need) to be enabled to provide good palliative care’

7 Meeting palliative care needs in dementia

7.1 At present, existing hospices and palliative care services are unable to meet the need for better palliative care for people with end-stage dementia and their families. The numbers are too large, sources of funding unclear, and most services do not have the necessary experience and expertise in managing the complex behavioural and psychiatric problems of this patient group.

Some inpatient hospices and specialist palliative care units may choose to care for some end-stage dementia patients on occasions, where there are particularly complex physical needs, where the psychological and social issues for the families around death and dying are particularly complex, and where the patient’s prognosis is clearly poor. Community palliative care teams may also become directly involved in supporting people with dementia at home particularly, again, when the palliative care needs of the patient and family are particularly complex and where the prognosis is poor.

Palliative care services will, however, only be able to provide direct care to a small proportion of people living with dementia. What therefore is needed is for the health and social services currently providing care for people with dementia (need) to be enabled to provide good palliative care informed by the palliative care approach. Some people with dementia are already receiving excellent palliative care in both the community and in institutions. However this is not always the case.

7.2 Community palliative care teams have a key role to play in working with local general practitioners and community nurses to educate them in the palliative care approach and to help them apply this in their care of people with dementia. They are also well placed to provide support to the professional carers involved, whether in the home or in nursing homes. However, community palliative care teams have neither the expertise nor the capacity to meet the support needs of all informal carers in the community, however, and this issue needs addressing.

7.3 Barriers to providing better palliative care for patients living in nursing homes or in continuing care wards in hospitals include the reliance on unskilled staff and lack of expertise and understanding of the principles and practice of palliative care. Death and dying are often not addressed specifically, and staff are often ill equipped to deal with dying patients. Nursing homes within the independent sector are often isolated from the NHS and wider developments in healthcare and this can be a major barrier in accessing expertise in palliative care. Funding issues directly influence the ability of nursing homes and other institutions to provide high quality palliative care for people with dementia, both by affecting

‘Education in the palliative care approach is needed for all NHS staff in continuing care and psychogeriatric wards, as it is for nursing home staff. This would help dispel myths about death, encourage open and honest communication and promote expertise in end-of-life care’

the number of trained staff who can be employed, and by limiting access to educational opportunities.

Education in the palliative care approach is needed for all NHS staff in continuing care and psychogeriatric wards, as it is for nursing home staff. This would help dispel myths about death, encourage open and honest communication and promote expertise in end-of-life care.

Many local palliative care services are already involved in initiatives to help local nursing homes and continuing care wards provide better palliative care for people with end-stage dementia (Boxes 3–6). These initiatives need to be evaluated and the results disseminated widely.

- 7.4 Demands for high quality end-of-life care for younger patients with dementia may increase over the next decade. Due to the success of triple-therapy, the proportion of people dying from AIDS/HIV is decreasing. However, many patients will live with significant morbidity, including AIDS-related dementia. In addition, the continued success of triple-therapy cannot be guaranteed. Given the increased prevalence of HIV infection, the demand for care for people with AIDS-related dementia is likely to increase. In addition, it is possible that the number of patients with new variance CJD would also increase over the next decade.

Box 3: A pro-active approach from a hospital based Macmillan nurse

Hospital based palliative care teams and Macmillan nurses can play a key role in increasing palliative care skills in the hospital. For example, a Macmillan nurse in a hospital in the North of England works closely with staff on a long-term care ward for older people with mental health problems. As a result, staff have undertaken training in the palliative care approach and became familiar with a range of palliative care nursing skills, interventions and specialist equipment: one staff member is undertaking the ENB 931 course in palliative care and one nurse now holds a Diploma in Palliative care. The use of transdermal patches has been introduced, and a syringe driver has been purchased.

Box 4: Collaborations between specialist palliative care and mental health agencies

A hospice in Scotland has worked closely with the national dementia research centre to improve palliative care for people with dementia. They have developed joint educational material for mental health and specialist palliative care professionals, have held joint study days and run short courses on the palliative care approach for mental health care workers.

Nursing homes geared to the care of older patients are unlikely to provide the most appropriate care for the younger patients. Hospices and specialist palliative care services should be aware of the likely increase in demand for inpatient care for younger patients with these conditions and should be considering in conjunction with local health commissioners and other services what role they would envisage taking in the care of these patients. Their decisions would have consequences for the future design of hospices and specialist palliative care units, and for their funding.

Box 5: Introducing the palliative care approach in a psycho-geriatric setting

In a NHS day centre for people with dementia, staff from the day hospital and from specialist palliative care services developed a strategy for providing care within a palliative framework. Attitudes of nursing and care staff – many of whom were said to believe in the aggressive treatment of illness at all cost – were a major barrier to overcome. Diagnosing pain and pain control were identified as major issues. Effective skills and appropriate knowledge in this area was thought to be lacking within the care team, especially in determining appropriate levels for medication for pain control. A specific training budget was therefore established and training provided both for qualified nursing staff and for care staff, particularly in the issue of tissue viability and (with input from a speech therapist) in relation to communication issues. Qualified nursing staff then undertook specific training in palliative care such as ENB 931 course. Staff felt the quality of individual care plan had improved, particularly in relationship to information regarding the management of physical care.

Box 6: Palliative care link-nurse in a psycho-geriatric setting

A ward in a general hospital offering continuing care, respite and a sit-in service to older people suffering from organic mental health disorders recognised the need to provide appropriate palliative care. A palliative care link-nurse was chosen as the best way to incorporate palliative care into the service. A psychiatric nurse on the ward with no general nurse training adopted the role. She was initially seconded to work for one day a week at a local hospice. She attended an in-service care for dying training programme at the hospice and has subsequently attended an ENB 931 course. She is attending a number of multi-disciplinary study days and attends a palliative care interest group where information and expertise are exchanged with specialist palliative care nurses. She established a ward resource file of up-to-date information on pain and symptom control and the use and management of syringe drivers and information on specific palliative care services. Information is also disseminated to other staff about palliative care study days and relevant training. The service believe that staff are now more confident and provide adequate support to carers who have difficulty making informed choices about care and treatment of terminal illness. The staff are now more aware of different resources available, medical staff are encouraged to recognise the need for improved pain relief, and the staff are now more aware of how to address sensitive issues, such as active resuscitation, with client's relatives and carers.

PRIORITIES FOR RESEARCH AND DEVELOPMENT

- ❖ Investigation of the views of users and potential users as to appropriate palliative care provision in severe mental illness and dementia.
- ❖ Assessment of pain and other symptoms in demented patients.
- ❖ Development of guidelines for treatment of pain in patients with severe mental illness, a third of whom are likely to have history of a drug misuse and/or alcoholism.
- ❖ Development of joint training schemes for palliative care and care of the elderly health professionals, and the evaluation of effectiveness of such schemes in changing attitudes and improving the knowledge of (a) palliative care specialists in the care of patients with confusion and (b) of care of the elderly specialists in end-of-life care.
- ❖ The organisation and delivery of palliative care support and services to nursing and residential homes and to NHS continuing care units to improve end-of-life care.

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The Scottish Partnership Agency (SPA) is the national umbrella and representative body for palliative care in Scotland. It aims to promote the development, extension and improvement of palliative care services and to ensure that high quality care is available throughout Scotland for people with life threatening conditions and their families.

The SPA has a membership of 78 voluntary and statutory organisations involved in the provision of palliative and cancer care. They include:

- Hospices and Specialist Palliative Care Services
- Health Boards and NHS Trusts
- National Charities & Patient Support Organisations
- Associations of Health Professionals

Through the SPA member organisations work in partnership to:

- share information and expertise
- communicate on palliative care issues to the appropriate committees and departments of the Scottish Executive
- develop and publish guidance on all aspects of palliative care
- collaborate in joint action
- collaborate with the National Council for Hospice and Specialist Palliative Care Services on UK-wide issues.

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