Joined up thinking
Joined up care…

Report of the Scottish Partnership for Palliative Care Big Lottery Fund project:

'Increasing access to palliative care for people with life-threatening conditions other than cancer'

November 2006

LOTTERY FUNDED

Scottish
Partnership
for Palliative Care

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Foreword

In Delivering for Health, we recognised that Scotland is changing. The health service needs to adapt to these changes. Our population is ageing; more people are living with long term conditions. Advances in medical knowledge and improvements in health services have increased life expectancy, but we cannot prevent the inevitable. We have to adapt the way we care for people during their lifetime, and this includes the way we care for people when they are dying.

The health service understandably targets its resources and energies on protecting life. That is absolutely as it should be, but we must also make sure this doesn't neglect the needs and expectations of those for whom there is no cure. Specialist palliative care offers a much valued service, addressing a range of medical, social, psychological and spiritual needs of both the patient and their family. Specialist palliative care has always had close associations with cancer services. The challenge we face now is how to extend that quality of palliative care to everyone, whatever their illness.

This report is timely. It shows clear recommendations which would lead to a truly universal palliative care service. I know that the recommendations are challenging. It will mean rethinking the way resources are allocated. Some clinicians might have to look again at their own understanding of the dying process. But I hope that this report sets out a way forward to which all NHS Boards in Scotland would aspire.

Andy Kerr

Andy Kerr

Minister for Health and Community Care

Acknowledgements

The Scottish Partnership for Palliative Care would like to thank all those who contributed to the project, particularly members of the steering group and professional and user reference groups, the staff team and all those individuals and organisations who responded to or facilitated the consultation process. This includes all those people with conditions other than cancer and informal carers who took the time to tell us about their personal experiences, the voluntary organisations who helped us to access these people and the health and social care professionals who took time out of their busy working lives to give thought to the issues raised in our consultation questionnaires.

Special thanks are due to Marie Curie Education Service for their contribution in developing, delivering and evaluating the project study day.

Finally, the Partnership would like to express its thanks to the Big Lottery Fund for making this work possible and for their enthusiastic support throughout the project.

Contents

I

Introduction

1. Introduction

Background

1.1 The Scottish Partnership for Palliative Care is the national umbrella and representative body for palliative care in Scotland. In 2003, the Partnership was successful in its bid, developed in consultation with a range of other organisations, for a Big Lottery Fund (BLF) grant to undertake a three year project 'Increasing access to palliative care for people with life-threatening conditions other than cancer.'

1.2 A full time project manager reporting to the Director of the Scottish Partnership for Palliative Care was appointed, and a steering group led by the Chairman of the Partnership was established as a sub group of the Partnership Council. A part-time education consultant, based with and supported by the Marie Curie Education Service in Scotland, was appointed for the second half of the project.

1.3 Two reference groups were also established, one of users and carers and the other of health and social care professionals, to ensure that the viewpoint of the groups of people who would be involved in contributing to the project and who would ultimately benefit from it (ie people with progressive life-threatening conditions and their families/carers and the doctors, nurses, therapists and others involved in caring for them or planning their care) was also reflected in the planning and implementation of different aspects of the project. The reference groups met at six monthly intervals throughout the life of project, and made a valuable contribution to its development.

1.4 The project bid developed from a growing recognition that people with progressive non-malignant conditions should have the same opportunity to benefit from good palliative care as those with cancer. This was reflected in a series of Scottish Executive policy statements:

- *Our national health, a plan for action a plan for change* (2000) recognised that palliative care should be available to all on the basis of need not diagnosis
- *Cancer in Scotland: Action for change* (2001) acknowledged the wider application of palliative care beyond cancer
- *Coronary Heart Disease and Stroke Strategy for Scotland* (2002) indicated that palliative care should be available to all with end stage heart failure.

1.5 The Scottish Partnership for Palliative Care welcomed the commitment of the Scottish Executive to the aim of increasing access to palliative care to those with life-threatening conditions other than cancer. It was clear at that time, however, that a considerable amount of work needed to be carried out, particularly in the field of education and training, before this aim could become a reality. While it was generally accepted that the palliative care expertise which had been developed over many years' experience with cancer patients was in principle transferable to the care of those with non-malignant conditions, this had yet to happen to any extent in practice. There was a growing awareness of the work which needed to be done in understanding the palliative care needs of people with progressive and life-threatening non-malignant disease and in identifying some of the pathways by which those needs might be met. This project was intended to contribute to that agenda, and to lay some of the groundwork for future developments.

What is palliative care?

1.6 Palliative care is about quality of life. It is the term used to describe the care that is given when cure is not possible. It means 'relieving without curing'. It addresses all of a persons needs, mental and emotional as well as physical. It is commonly associated with the later stages of cancer. However, palliative care is also relevant in a wide variety of incurable conditions, and from the time of diagnosis onwards.

1.7 Palliative care is person-centred care. Its aim is to maintain, and as far as possible improve, the quality of life of people with non-curable progressive illnesses and those closest to them. It is based on recognising and respecting the unique individuality of the person cared for. Palliative care is concerned with:

- controlling pain and other distressing symptoms
- helping people and those closest to them cope with the emotional upset and practical problems of the situation
- helping people to deal with emotional/spiritual matters which may arise from serious illness
- helping people to live as actively as possible despite serious illness
- supporting families and friends throughout the illness of a loved one and in bereavement.

1.8 Palliative care can be provided at any stage after diagnosis of a life-limiting illness or condition, as well as in the last few days, weeks or months of the illness when a progressive decline becomes clear. Depending upon a person's needs, different levels of palliative care may be provided by a number of different people and services.

Palliative care approach

1.9 A palliative care approach is a basic approach to caring for people as individuals which emphasises the importance of good communication and of respect for individual autonomy and dignity. It recognises that people may have needs which are physical, social, psychological or spiritual, or a combination of these. Such an approach is particularly appropriate when dealing with those who have long-term progressive conditions and should be adopted by anyone in a caring role, whether health and social care professionals, volunteers, family or friends.

General palliative care

1.10 General palliative care is care that is based on the understanding and practice of palliative care principles. These include:

- a focus on quality of life which includes good symptom control
- a whole person approach which takes into account the person's past life experience and current situation
- care which encompasses both the person with the life-threatening illness and those that matter to that person
- respect for patient autonomy and choice
- emphasis on open and sensitive communication.

1.11 General palliative care is provided for those who need it as part of the routine care provided by a person's usual professional carers (doctors, nurses, care assistants etc) whether at home, in a care home, or in hospital.

Specialist palliative care

1.12 Specialist palliative care is based on the same principles of palliative care, but can help people with more complex palliative care needs. Specialist palliative care is provided by specially trained multi-professional specialist palliative care teams and can be accessed in any care setting.

The project

1.13 The project focussed on the experiences of people with ten specific progressive, life-threatening conditions and those caring for them. These were:

- cystic fibrosis
- dementia
- heart failure
- HIV/AIDS
- motor neurone disease
- multiple sclerosis
- muscular dystrophy
- Parkinson's disease
- renal failure
- respiratory failure.

It was recognised, however, that it would not be possible within the scope of the project to produce any analysis or outcomes specific to individual conditions. It was also agreed to exclude Huntington's disease from much of the consultation process following award of a BLF grant under the same palliative care programme to the Scottish Huntington's Disease Association.

Project aims

1.14 The overall aims of the project as agreed with the Big Lottery Fund were:

- to increase access to palliative care support and services for people with life-threatening conditions other than cancer
- to promote the integration of palliative care principles in the care of people with a range of progressive life-threatening conditions.

1.15 Specific objectives were identified as follows:

- to identify some of the common palliative care needs of people with specific non-malignant progressive conditions and to promote wider recognition of these
- to understand some of the barriers involved in the difficulty often experienced by these groups in accessing appropriate palliative care
- to begin to identify possible ways of overcoming the barriers and meeting the needs identified.

1.16 To attempt to meet these objectives a Scotland-wide consultation process was carried out. Questions were asked of:

- people with conditions other than cancer and informal carers about their palliative care and information needs
- professional carers about their educational support needs
- NHS Boards, local authorities and voluntary organisations about their needs assessments and planned palliative care strategies.

Consultation process

1.17 The consultation process was carried out mainly by written questionnaires, developed by the project steering group with input from the professional and user reference groups. The process took place in stages, with analysis of the responses from one group informing the content of consultation with the next. Separate questionnaires (see Appendix 1) were developed for:

- people with life-threatening conditions other than cancer
- informal carers
- generic health and social care professionals
- providers of specialist palliative care
- NHS Boards
- local authorities
- voluntary organisations.

Following analysis of all questionnaire responses, a number of one to one interviews were held with individuals, both lay and professional, to explore further some of the areas identified through the consultation process.

Consultation: people with life-threatening conditions other than cancer and informal carers

1.18 Separate written questionnaires were developed for people with conditions other than cancer (the same questionnaire was used for all conditions) and for informal carers. Both of these questionnaires were piloted using one to one interviews and slight amendments were made following the pilot.

1.19 Questionnaires were distributed in the autumn of 2004 by clinical nurse specialists and representatives from voluntary organisations who were known to the people involved in consultation. In this way, participation in consultation was handled sensitively and only people who felt happy to do so were asked to participate. The numbers of returned questionnaires for both groups were in excess of the target numbers and in excess of the response rate which might have been expected from this target group.

Consultation: generic health and social care professionals

1.20 This group consisted of health and social care professionals working in areas other than specialist palliative care, and included professionals working with specific conditions. The same questionnaire was used for all professional groups and was piloted by post. Written questionnaires were distributed in autumn 2004 to representatives of the following groups identified through members of the steering group, professional and user reference groups and through the Partnership's existing network of contacts:

- care home staff
- community nurses
- dieticians
- general practitioners
- hospital nurses
- junior doctors
- medical consultants
- occupational therapists
- physiotherapists
- practice nurses
- social workers
- specialist nurses
- speech and language therapists.

Consultation: providers of specialist palliative care

1.21 The questionnaire developed specifically for providers of specialist palliative care was piloted by post in summer 2005 and distributed in autumn 2005 to the following professional groups in all adult hospices and hospice units in Scotland:

- chaplains
- community palliative care nurses
- community palliative care nurse specialists
- consultants in palliative medicine
- day hospice team members
- dieticians
- hospice/hospice unit/palliative care unit nurses

- hospital palliative care clinical nurse specialists
- junior doctors
- managers/team leaders
- occupational therapists
- pharmacists
- physiotherapists
- senior hospice nurses (ward manager and above)
- social workers.

Consultation: NHS Boards, local authorities and voluntary organisations

1.22 Separate questionnaires were developed for consultation with the fourteen NHS Boards, thirty two local authorities and the following ten voluntary organisations representing conditions covered by the project:

- Alzheimer Scotland – Action on Dementia
- British Heart Foundation
- British Lung Foundation
- Cystic Fibrosis Trust
- Multiple Sclerosis Society Scotland
- Muscular Dystrophy Campaign
- Parkinson's Disease Society
- Scottish Kidney Federation
- Scottish Motor Neurone Disease Association
- Waverley Care Trust (HIV/AIDS).

Project outcomes

1.23 Analysis of consultation responses led to two additional outcomes of the project:

- development and piloting of a palliative care study day designed to meet the identified education needs of generic health and social care professionals
- development of an information support checklist to help NHS Boards, Community Health Partnerships, local authority areas and others ensure that the identified information support needs of people with life-threatening conditions other than cancer and informal carers are met.

Details of these are included as appendices to the current report.

This report

1.24 The content of this report and the conclusions and recommendations it contains are based on the content and analysis of the consultation process outlined above. Key themes emerged, which form the basis of the report's structure and recommendations.

1.25 Extensive use is made of quotations from consultation questionnaires. Many of these illustrate examples of good practice and existing collaborative working. Quotations from NHS Boards and local councils have been attributed in order to facilitate further opportunities for networking and the sharing of experience.

1.26 The Scottish Partnership for Palliative Care believes that this report provides a valuable opportunity for the views of service users, providers and planners throughout Scotland regarding access to palliative care for people with life-threatening conditions other than cancer to be heard. We hope that the information gathered will be of use to all concerned and that in its process and outcomes the project has helped to point the way to realistic and achievable ways of working towards equitable access to appropriate palliative care for all.

2

Consultation responses: recognising the needs

2. Consultation responses: recognising the needs

2.1 The needs presented in this section are those identified through the Scotland-wide consultation process. Due to the differing perspectives of respondents, slight differences are apparent in the needs identified by each group. However, it is clear that overall, respondents from all consultation groups have identified very similar needs which require to be met before optimum palliative care can be provided for people with conditions other than cancer.

> ‘There is a great need for palliative care in a wide variety of settings now that peoples’ life expectancy is longer. Increased and extended survival rates mean that people are living with debilitating disease for longer, but that their needs are becoming more complex as a result of not only physical, but emotional, spiritual and psychological pressures that this causes.’
>
> clinical specialist occupational therapist, specialist palliative care

2.2 During our consultation with NHS Boards, local authorities and voluntary organisations, we asked about the needs of people with conditions other than cancer. Seven of the twelve NHS Boards who responded to consultation had carried out detailed needs assessments for this group. Of the Boards who had not yet completed needs assessments, the majority planned to do so, although one identified the need for ring fenced money from Scottish Executive Health Department (SEHD) before this could be done. All Boards that had carried out detailed needs assessments for this group said that the findings were reflected in their current palliative care strategies or in the Board’s future plans.

2.3 Ten of the twelve NHS Boards who responded to our consultation said that they had carried out scoping of the palliative care services available, via either health or social care, to this group. Those who had not yet carried out scoping had plans to do so in the future.

2.4 Eight out of the twenty seven local authorities who responded to consultation had detailed palliative care needs assessments for this group of patients and ten had carried out scoping of the palliative care services available for this patient group. Some local authorities told us that single shared assessment documentation was being used to assess individual needs.

2.5 Many of the needs identified could equally be applied to people with malignant conditions, although all groups highlighted uncertain disease trajectory with fluctuating symptoms as the feature that sets the needs of people with non-malignant conditions apart from those of people with malignant conditions. The needs identified have been classified under the following headings:

- information
- practical help
- symptom management
- joint working
- psychosocial
- education and training.

Information needs

2.6 Through our consultation process, we have been able to identify information needs that are priorities for people living with non-malignant conditions, their informal carers and the health and social care professionals involved in their care. This section includes information needs identified by these three groups. The needs identified appear in the order of priority given to them by consultation respondents.

Information needs: benefits and financial matters

2.7 The diagnosis of a life-threatening condition has far reaching consequences. Amongst these is the reduction in or loss of income for the individual concerned as their disease progresses. Informal carers may also face the same financial losses as they spend increasing amounts of time in their caring role. Both groups identified the need for information about their entitlement to financial help and when it is appropriate to apply for benefits. This information needs to be made available in time for people to make claims before they reach a financial crisis point. Young people need information about how to access independent living funds to provide 24 hour care should they choose to move away from their parents' home.

Information needs: holidays and travel

2.8 People with conditions other than cancer need information on all aspects of ordinary living including holidays and travel. This includes accurate information about using public transport, accessible facilities, how to get holiday insurance and how to get help whilst away on holiday.

> 'We have had very bad experiences taking holidays because the places sounded good, but when we got there the disabled facilities were really poor.'
>
> husband of a lady with multiple sclerosis

Information needs: how to get help to give informal carers time off

2.9 People with progressive non-malignant conditions were concerned about the health and wellbeing of their informal carers and were keen to ensure that they are given time off, but both they and their informal carers needed information on how to facilitate this. Information is needed on local facilities such as day centres, respite care and buddy schemes and how to access them.

Information needs: where to find help, support and advice

2.10 Although there is a wide range of help, support and advice available for people with conditions other than cancer and informal carers, our consultation respondents told us that it can be difficult to find. People with non-malignant conditions and informal carers want information to be provided which directs them to help, support and advice available to them in their local area. They also want to know how to access more care as their needs increase.

2.11 Similarly, generic health and social care professionals also highlighted this area as a priority information need, as they need to be aware of the services available in their area before they can provide information to their patients and informal carers.

2.12 Many people with non-malignant conditions want information that helps them to maintain their independence for as long as possible. This includes information on alternative work patterns and symptom management.

2.13 Young adults share these information needs and have additional needs around relationship issues and information for partners or prospective partners about their condition. The genetic nature of some life-threatening conditions means that young adults also need information on family planning.

Information needs: condition-specific information

2.14 There is a need for people with non-malignant conditions and informal carers to receive information which acknowledges their situation and gives useful advice. People told us that they need realistic information about the impact of their condition and its likely course, including prognosis. They also need information on condition-specific voluntary organisations and support groups and how to access them. Information provision needs to be given at an appropriate time, which will vary between individuals.

2.15 People need to know how to live with their condition in its current form, and to be able to anticipate their future needs. They need information on how to get the best out of their situation, whilst acknowledging that things have changed and planning for the future. Respondents to the consultation told us that they wanted to receive this information from someone who understands the condition and has experience of caring for people with it.

> 'Just what to look out for, how to cope when things get worse, what people to contact and more information on care other than leaving everything to my family.'
>
> lady with multiple sclerosis

Information needs: information for professionals

2.16 There is a need for high quality information sharing between professionals about their patients and their plan of care. Health and social care professionals also need information about conditions that they may come across only rarely in their career. Generic health and social care professionals need to know when and how to make a referral to providers of specialist palliative care and what level of input to expect from colleagues in this area. Both generic health and social care professionals and providers of specialist palliative care need to know where to get condition-specific advice when involved in the care of people with non-malignant conditions.

Practical help

2.17 People with life-threatening conditions other than cancer may need help over a period of many years and their needs often fluctuate during this time. The unpredictability of their disease trajectory and care needs can be a particular challenge to people with conditions other than cancer, their informal carers, the health and social care professionals involved in their care and planners of health and social care services.

Practical help: assessment

2.18 In light of the length of time general palliative care is needed by many people with life-threatening conditions other than cancer, consultation respondents of all groups identified the need for regular assessment of the needs of people with conditions other than cancer and informal carers.

2.19 The needs of people with non-malignant conditions can change quickly. Some conditions are characterised by a rapid deterioration, whilst others have fluctuating symptoms. In both cases regular reviews of needs and flexible services are needed.

Practical help: access to services

2.20 Where personal care is provided by paid carers, people with non-malignant conditions want to receive this care from carers who understand their condition and how it affects them. They want continuity of care from a small group of carers with whom they can develop a rapport and who respect them as an individual and help them to maintain their privacy and dignity. In the case of young adults, younger carers can be easier to relate to. Care packages need to be individually tailored to take account of the views of patients and carers.

2.21 Most importantly, people with non-malignant conditions need their care to be co-ordinated and to facilitate this, they need a key worker/care manager in place who can ensure all needs are met whilst avoiding duplication.

2.22 Where personal care is provided by informal carers, the relationship between the person being cared for and the carer needs to be considered. As children get older, it may no longer be appropriate for their parents to give personal care. Older carers may experience deterioration in their own health that affects their ability to maintain their caring role. Regular review of informal care arrangements is therefore important.

2.23 In addition to provision of personal care, there is also a need for general domestic help. This includes help with lifting and carrying and doing general household tasks and minor household maintenance.

> 'Who will be responsible for window cleaning, curtain washing and basic household duties which worry so many people on their own?'
>
> wife of a gentleman with dementia

> 'Policies for delivering home care services should recognise the need to undertake domestic tasks, shopping etc in such situations as well as the 'enabling' role, which is the primary focus of the council's home care service'.
>
> Perth and Kinross Council

Practical help: equipment and adaptations

2.24 The progressive nature of the conditions covered by the project means that a rapid response to requests for equipment and adaptations is needed. At present, people with progressive conditions go on a common waiting list for equipment and adaptations. The rapid deterioration seen in some conditions means that there is a need for provision of equipment whilst it can still be used so that the person and their carer can have an improved quality of life.

> ‘We have been waiting for a ramp to be fitted. You go on the same planning permission for this as everyone else. There’s no priority for the disabled. By the time we get it, it may be of no use. He could have a power chair and that’s ready but there’s no point having it until we’ve got the ramp. We’ll have to pay the third party insurance ourselves for the power chair’.
>
> wife of a gentleman with motor neurone disease

2.25 The need for timely provision of equipment to meet the needs of people with conditions other than cancer was also identified by the health and social care professionals who took part in our consultation.

> ‘There is a need for a central resource store for equipment with a facility for speedy access to equipment and adaptations. Patients cannot wait for six months for these.’
>
> occupational therapist working in specialist palliative care

Practical help: financial matters for patients and carers

2.26 In addition to needing information on financial matters, many people find making a claim for benefits and understanding financial matters daunting and confusing and so need help in this area. This may take the form of help to understand how and what to claim and to ensure all potential benefits are claimed, and/or physical help to complete forms. Signposting to reliable financial advice is also needed as many people with progressive non-malignant conditions and their informal carers have experienced significant unforeseen changes to their financial circumstances.

Practical help: respite care

2.27 It is clear that there is a need for people with conditions other than cancer to be able to access respite care. There is a particular need for age appropriate respite care to avoid young people receiving respite in facilities geared around the needs of older people. The staff providing respite care need to have an understanding of the person’s needs in relation to their condition. Flexibility is also important so that respite can be accessed for variable periods of time.

> ‘There should be more respite places for people my age (35-44) instead of just going to an old folks home.’
>
> lady with multiple sclerosis

> ‘It would help if respite periods covered weekends and allowed carers an unrestricted length of holiday other than fitting in with the times given.’
>
> husband of a lady with multiple sclerosis

2.28 Parents of children who require respite care need respite facilities which are within a reasonable distance from home to allow them peace of mind whilst their child is away.

> 'They expect me to send my child for respite miles away to strangers – what parent would send their children to someone they didn't know in a place they didn't know?'
>
> mother of a child with muscular dystrophy

2.29 Teenagers and young adults need to have respite care provided which is appropriate to their age and needs.

Practical help: support for carers

2.30 Many people with conditions other than cancer expressed concern about their carers' workload and felt that more help was needed for their carers. The level of care given by carers increases over time and informal carers, many of whom are aged over 65, gradually find themselves in physically and mentally demanding roles with little or no respite.

2.31 Many carers told us that they have experienced a detrimental effect on their own health as a direct result of caring. Just over half of the respondents told us that they had discussed this with someone. Most respondents said that they were aware of where to go to find additional help, support and advice if they needed it. Carers are entitled to a carers assessment and need help to get this and to make a contingency for care provision should they be unable to continue in their caring role for any reason. Although they were aware of where to go for additional help, it was clear from their comments that some carers were receiving little or no help.

> 'I can't go shopping, visit grandchildren or 92 year old mother, get hair done or even post a letter. Thank goodness for internet shopping.'
>
> wife of a gentleman with heart disease

Symptom management

2.32 The symptoms causing most concern to people in all groups were breathlessness, pain and reduced mobility. These resulted in reduced independence, difficulty or inability to go out alone and difficulty carrying out everyday tasks. Gradual, subtle changes in symptoms made it difficult for carers to recognise the changing symptoms and to know when to seek help. Regular assessment of symptoms by professionals is therefore needed. Unwanted side effects of symptom management also caused distress eg pain killers which left people feeling drowsy and unable to undertake day to day tasks which were otherwise within their capabilities.

2.33 Respondents highlighted the need for interventions such as therapeutic massage to be made available in addition to more conventional treatments.

2.34 People with conditions other than cancer felt that at times any symptom they experienced was attributed to their condition without further exploration to find another possible cause.

2.35 The symptoms in the person cared for that caused most concern to carers were breathlessness, pain and discomfort. Carers were distressed that they were not able to relieve symptoms completely and were afraid of potential outcomes eg if the person they cared for fell and injured themselves or stopped breathing. There was also concern that professionals did not always appear to recognise symptoms or to be concerned by them.

2.36 Generic health and social care professionals highlighted the need for expert advice on symptom control and better awareness of medications to alleviate symptoms. They also noted that symptoms in some groups may be difficult to establish due to cognitive or communication difficulties and that older people may have symptoms associated with several co-existing conditions.

2.37 Providers of specialist palliative care saw their main role in relation to symptom management as advisory (often via telephone) and felt that general symptom management needs could be met by generic health and social care professionals, with specialist palliative care advice/support being provided for those with the most complex needs.

Joint working

2.38 The need for a co-ordinated, team approach to care was identified by all groups in our consultation.

Joint working: patients and carers/health and social care professionals

2.39 People with conditions other than cancer, informal carers and health and social care professionals all identified the need for professionals involved in the care of people with conditions other than cancer to have a level of understanding of their condition and to know where to access condition-specific specialists for further advice.

> ‘Access to a multidisciplinary team totally familiar with the condition as it affects me.’
>
> gentleman with multiple sclerosis

Joint working across professional groups and care settings

2.40 Many people have access to care from a variety of sources. This can result in duplication among professionals and disjointed care. There is a clear need for a co-ordinated multidisciplinary approach to care with a key worker/care manager to provide a single point of contact, ensure the identified needs are met and avoid duplication. There is also a need for improved communication between the many professionals involved in the care of people with conditions other than cancer and this is linked with the need for better co-ordination between services.

> 'It would help if there was a 'joined up' approach to dealing with benefits, equipment etc. So often you have to chase up these things and spend valuable time and effort dealing with different agencies.'
>
> mother of a son with muscular dystrophy

2.41 Consultation with generic health and social care professionals highlighted the need for a palliative approach to be taken in the care of all people with life-threatening conditions other than cancer. Clear treatment plans and care pathways are needed to prevent crises as far as possible, with access to emergency and out of hours health and social care if needed. There is also a need for national standards of care, improved transition from hospital to home and more outreach/inreach care. Professionals also identified the need for clarity around the services to be offered, who they should be provided by and in what care setting.

> 'The general information passed on when community patients are referred is very poor. Often the referral may say 'palliative care', but this is the only information we get. We need to know a clear aim of treatment, information about the patient's understanding of their condition and prognosis and information about the other services and professionals involved.'
>
> dietician working in general setting

2.42 Care home staff told us that they care for people with multiple co-existing conditions and that a palliative approach is needed for all people in their care. Some residents, however, have more complex needs.

> 'Often patients in my care require a higher level than general palliative care but not specialist palliative care.'
>
> care home matron

Joint working: health and social care

2.43 The NHS Boards that responded to consultation identified developing a model of care to offer equitable and appropriate palliative care across a range of settings for people with both malignant and non-malignant conditions as a key issue in implementing palliative care strategies which specifically include the palliative care needs of people with life-threatening conditions other than cancer. NHS Boards also told us that some areas of inequity had been identified in palliative care services available via health or social care for this group. They also highlighted a need to allocate resources appropriately, and to better utilise existing resources. Both NHS Boards and local authorities identified the need for improved collaboration between health and social care for people with conditions other than cancer.

> 'Better communication and co-ordination to harmonise the agendas of both organisations and make connections between services – it is more the connections between services than the absence of services.'
>
> NHS Tayside

> 'There is a need to identify where roles and responsibilities lie and where gaps and overlaps exist.'
>
> West Dunbartonshire Council

Joint working: access to specialist palliative care

2.44 The need for joint working between generic health and social care professionals and providers of specialist palliative care was recognised by both of these groups. Generic health and social care professionals want to work with colleagues in specialist palliative care for advice and input if necessary. Providers of specialist palliative care want to work largely in an advisory role, directing more input to people with the most complex needs, with the generic team maintaining overall responsibility for the patient.

Joint working: paediatric and adult services

2.45 As children with life-threatening conditions other than cancer grow up they need to make the transition from paediatric to adult services. They and their families have formed relationships with the health and social care professionals involved in their care and have known the services, and in some cases the professionals, throughout their lives. They and their families therefore need this transition to be as well planned and co-ordinated as possible.

2.46 Children and young adults with non-malignant conditions have an additional need in terms of education. During school holidays, parents need additional support to care for their child at home.

Psychosocial support needs

Psychosocial support needs: advice

2.47 People with conditions other than cancer want to have practical advice on how to live with their condition, how to maintain optimum health and prevent problems. The condition-specific clinical nurse specialist (CNS) was seen as an important and much appreciated source of advice. This role was seen by many respondents of all groups as one that should be better resourced to allow people with conditions other than cancer and informal carers to benefit from it as much as possible.

> 'The CNS is brilliant. She gives us choices and is there for us. I have the chance to talk to her on my own and she has told me what to expect in the future. She will meet me for a coffee if I need to talk things through away from my husband.'
>
> wife of a gentleman with motor neurone disease

2.48 Respondents from some groups, particularly those with heart failure, said that they were scared to do too much, but wanted to be shown what they can safely do. This would improve confidence and morale. Some respondents from all condition groups also wanted to be able to call a help line for advice and support.

Psychosocial support needs: emotional support

2.49 All our consultation groups identified the need for emotional support for people with non-malignant conditions, their informal carers and the health and social care professionals involved in their care.

2.50 People with conditions other than cancer told us that they need support and advice on how to deal with their condition. They spoke of living with a progressive life-threatening condition as being a lonely and isolating experience for the person cared for and the carer, and said that they wanted to have their changing situations and relationships acknowledged. These groups wanted the professionals involved in their care to have an understanding about their condition and its effects.

2.51 Some people also wanted to talk to someone of the same age and/or someone with the same condition as themselves. They wanted to know where to go to get additional help, support and advice and to have realistic expectations of what would be available when this input is sought.

2.52 People with conditions other than cancer and informal carers need to be empowered and enabled to help themselves as far as is reasonable and practical, and to represent themselves when their needs are reviewed and future needs anticipated. To do this they need to be well informed and involved in planning all aspects of care, rather than simply being told what is going to happen.

2.53 Emotional support for carers includes the need for respite to provide some time away from the caring role. Many informal carers receive little or no respite care:

> 'Occasional respite – I have not been away from home for more than four hours at a time for the last six and a half years.'
>
> husband of a lady with multiple sclerosis

> 'Overnight care as well as day care is taxing. The occasional night off for sleeping would be a benefit.'
>
> wife of a gentleman with Parkinson's disease

2.54 Since many carers expect to have to give all the required care, they can experience a great deal of guilt when the person they care for is admitted into a hospice or moves into a care home. Carers want to be confident that they will be asked about the needs of the person they care for and that they will be listened to. Consultation respondents told us that this is particularly important when the person being cared for moves into a care home. Health and social care professionals also identified the need for after care support for carers following such a move.

2.55 When the person being cared for is a child or young adult, the needs of the whole family should be considered and emotional support given should be appropriate to the needs of the young person. This group may also have additional bereavement support needs.

> 'It's hard when their friends die. These young people grow up together and grow very close, then one of them dies and it's all very difficult.'
>
> mother of a son with cystic fibrosis

2.56 Professionals, people with conditions other than cancer and informal carers all recognised the need for support for informal carers. It is clear from our consultation that carers may find it very difficult to accept the condition and the resulting progressive changes in the person they care for. They need help to accept what has happened, and what the person they care for, and their life, is like as a result. Some informal carers identified the need to be able to talk to people in the same position as themselves and to know they are not alone. Other carers had developed their own coping strategies (eg hobbies that can be continued at home).

2.57 Professionals identified the need for emotional support for people with conditions other than cancer to acknowledge their changing situation and the multitude of losses they have experienced. This may be compounded by difficulties with communication and so this group may need additional time for their emotional support needs to be met. Some providers of specialist palliative care acknowledged that since many people in this group do not access hospice care, they can miss out on this important aspect of their care. If these people do access specialist palliative care professionals, it can often be the first time that they have been able to acknowledge openly and discuss issues around death and dying.

Psychosocial support needs: respect for individuality

2.58 People with conditions other than cancer and informal carers need to be treated with respect for their individuality. Many people with conditions other than cancer have lost the ability to continue hobbies and interests which contributed to making them the person they were before they developed a progressive condition. Loss of mobility and communication were identified as particularly significant factors in the struggle to maintain a sense of identity.

2.59 People with conditions other than cancer and their informal carers told us that they need:

- intelligent, empathetic responses to their illness
- honest, realistic information
- people to listen to what they say and to act on it.

2.60 It is important for people with conditions other than cancer and their informal carers to be able to have time to carry out activities of their choice. Most of the carers who responded to our consultation told us that they had only a few hours for this each week.

Psychosocial needs: work and social activities

2.61 Many people with progressive non-malignant conditions lose the ability to drive or to travel independently on public transport as their condition progresses. As a result of this and of general physical deterioration they also experience a reduction in their social lives and may no longer be able to maintain their previous hobbies and interests. Accompanied trips require significant additional planning and may be subject to other restrictions. People with conditions other than cancer want to maintain flexibility and choice in the way they live their lives. To do this they need help with transport (eg dial-a-ride services, volunteer drivers, local authority transport) and options of accessible social opportunities so that they can go to places of their choice rather than the only places they are able to access.

> 'Everything has to be done by the clock and I feel this is a huge restriction on my life. If things were more flexible, I'd be able to get out more. At the moment I go out only once a week, but even this is a rush, as I need two people to help me back into my chair and they only have limited time, which spoils my shopping trip as I am constantly clock watching.'
>
> lady with multiple sclerosis

2.62 People with non-malignant conditions who are of working age need help to negotiate how to keep their jobs or adopt flexible working patterns to accommodate their needs. As children with non-malignant conditions reach adulthood they need help to access suitable work opportunities.

> 'If I had had help to advise me how to keep my job or change my hours I might have been able to work for longer than I did before I had to give up work.'
>
> lady with multiple sclerosis

Psychosocial support needs: support for professionals

2.63 There is also a need for support for staff involved in the care of people with conditions other than cancer via mechanisms such as clinical supervision, staff support groups and mentorship. Many professionals are lone workers who feel isolated or who work in remote areas with little or no peer support.

> 'I work alone in a primary care setting and often find it distressing/emotionally draining dealing with people with life-threatening illnesses. As all my colleagues are based on different sites, I often feel I have no one to off load to. How can we care for others if we can't care for ourselves?'
>
> generic physiotherapist

2.64 Providers of specialist palliative care were concerned about caring for people with malignant conditions and those with non-malignant conditions in the same care setting.

> 'Having an in-patient unit caring for such diversity has an emotional and physical cost to staff and also to the patients themselves.'
>
> clinical team leader, hospice

2.65 Generic health and social care professionals identified the following priorities for their education and training needs in psychosocial support:

- being comfortable with their own spiritual issues
- coping with emotional distress and depression amongst those they care for
- providing emotional support to carers
- supporting people in expressing their hopes, fears and anxieties and the things that are important to them.

Education and training

Education and training: people with conditions other than cancer and informal carers

2.66 People with conditions other than cancer and informal carers highlighted the need for training for informal carers. This included training in:

- communication difficulties
- diet and feeding
- moving and handling
- when to seek further help.

2.67 The concerns identified by informal carers about symptom management issues also indicate that training on the management of the symptoms most common to all groups would also be very useful.

2.68 Less than half of the informal carers who responded to our consultation had received some form of training aimed specifically at informal carers. Of these, the majority had found the training useful. The vast majority of those who had not received any training said that they would find it helpful.

> 'It seems elementary to me, when all NHS staff are given lifting and handling training, that unqualified people (like my husband) struggling in difficult situations are given none.'
>
> lady with multiple sclerosis

2.69 People with conditions other than cancer and informal carers also identified the need for professional carers to be educated in the care of people with their condition. This mainly related to condition-specific aspects of caring.

> 'I feel too involved, which is very stressful. I feel that care workers should be more educated in dementia, and thus able to take the heavy role from the family member.'
>
> wife of a gentleman with dementia

Education and training: generic health and social care professionals

2.70 The need to educate all staff in the provision of a palliative approach for all people with conditions other than cancer was identified in consultation with NHS Boards and local authorities. These groups also recognised the need to include the public in education to raise awareness of what palliative care is.

> 'The biggest issue is education of health and social care professionals and the public. Many still believe that palliative care is for people with cancer who are dying.'
>
> NHS Orkney

2.71 These groups identified the need to enhance general palliative care skills amongst all health and social care professionals and to increase awareness amongst this group of the palliative care needs of people with conditions other than cancer.

2.72 Some respondents to consultation with local authorities identified a particular need for education for care home staff and professional home carers.

> 'A need to raise awareness in home care staff and increase home carers awareness of signposting has been identified'
>
> East Dunbartonshire Council

2.73 Condition-specific specialists highlighted the need for education about the palliative care needs of their patients.

> 'In multiple sclerosis there is doubt amongst generalists that the concept of palliative care is even appropriate. A great deal of education is required to overcome this.'
>
> multiple sclerosis clinical nurse specialist

2.74 As part of the consultation with generic health and social care professionals, we asked those who had received education and training in palliative care in the previous three years how relevant they had found it to their role. Most of the respondents told us that the education and training they had received was adequate for their role, but the majority of respondents in this group said that they would like the opportunity to attend education/training in palliative care.

2.75 The vast majority of this group of respondents told us that they felt that their knowledge of palliative care was adequate for their role and that they felt confident on a day to day basis in being able to meet the palliative care needs of any of their patients who needed it. However, it became clear from comments made on consultation questionnaires that the majority of this group believed palliative care to be terminal care and were confident in delivering end of life care, but did not appear to understand what palliative care actually is. We therefore recognised the need for education about the principles of palliative care for generic health and social care professionals.

2.76 We also asked this group to select their priorities for palliative care education and training from a list of twenty nine options. The top priorities for further education and training in palliative care (in the priority order identified in consultation) were:

- pain
- understanding available resources
- supporting people in expressing their hopes, fears and anxieties and the things that are important to them
- principles of palliative care
- providing emotional support to carers
- emotional distress
- managing professional interfaces
- fatigue
- making choices available to patients
- understanding different care systems.

Education and training: providers of specialist palliative care

2.77 Providers of specialist palliative care who responded to consultation told us that they needed condition-specific education to enable them to care for people with conditions other than cancer.

> ‘Each individual presents us with a huge learning curve.’
>
> team leader, palliative care day centre

> ‘I feel ignorant sometimes when visiting patients. Specialist palliative care needs are similar, but patients expect your general knowledge of their disease to be high’
>
> clinical coordinator, Macmillan Service

3

Consultation responses: identifying and overcoming the barriers

3. Consultation responses: identifying and overcoming the barriers

3.1 The consultation exercise identified a range of barriers experienced by people with life-threatening conditions other than cancer in accessing appropriate palliative care and highlighted possible ways of overcoming these.

3.2 It is important to point out that during the consultation, we found many people with conditions other than cancer and informal carers whose experience was excellent and who felt they had received very high standards of care. Health and social care professionals, NHS Boards and local authorities also described effective examples of high quality collaborative care that was anticipating and meeting the needs of people with life-threatening conditions other than cancer.

3.3 With that caveat, the barriers in this section are those most commonly identified in consultation through the experience of consultation respondents.

Information

3.4 The majority of people with conditions other than cancer and informal carers who responded to consultation said that the amount of information they had about the medical condition they or the person they cared for had was in accordance with their wishes. However many respondents told us that this information had not been made available to them and they had to seek it out themselves. Where respondents felt that they didn't have as much information as they would have liked, the key barriers identified were:

- difficulty gaining access to information
- difficulty understanding information.

Information barriers: difficulty gaining access to information

3.5 Some people with conditions other than cancer and informal carers told us that they had difficulty accessing information, both in written form and in conversation with health and social care professionals. A particular need for people with conditions other than cancer and informal carers was clear information about disease progression, future plans and eligibility for benefits.

> 'We need assistance with finding out funding available. There's no one to advise us about thresholds, council funding and savings advice. Help agencies are not able to define criteria for personal care allowance or nursing care allowance.'
>
> daughter of a lady with dementia

3.6 Some people with conditions other than cancer and informal carers told us that they had to spend time repeatedly trying to access information that was appropriate to them. In some cases people from these groups were reluctant to ask health and social care professionals for information because they felt they would be adding to their already high workload.

Information barriers: difficulty understanding information

3.7 Consultation respondents told us that some of the available information was very difficult to understand because of the terminology used.

> 'Some of the information you get is really bad. You can't understand the words. You need a dictionary to get through it.'
>
> wife of a gentleman with serious lung disease

3.8 Barriers were also identified in the transfer of information between professionals. Gaps in information included poor referral between professionals and lack of information about referral and acceptance criteria for different care settings.

Overcoming barriers to information: information support for patients and carers

3.9 We have used the information needs identified by people with conditions other than cancer and informal carers in consultation to develop an information support tool. This tool takes the form of a checklist which identifies the information that should be made available to all people with conditions other than cancer and their informal carers by the appropriate health and social care professionals involved in their care (see section 4 and Appendix 3). Much of the information is available already. However, it currently comes from a variety of different sources that people with conditions other than cancer and informal carers have to seek out for themselves.

3.10 It is clear from the project consultation that people with conditions other than cancer need to receive clear, concise, user friendly information as early as possible after the diagnosis of their condition. More information will gradually become necessary as their condition progresses. It is also clear that health and social care professionals working in both generic settings and in specialist palliative care need information on the services available to people with conditions other than cancer.

Information: recommendation 1

Recommendation 1: information support

Provision of information should be recognised as an important part of the proactive care of patients and carers. Steps should be taken to ensure that appropriate and locally relevant information is available to people with progressive non-malignant conditions and their informal carers from the point of diagnosis onwards. The information support checklist compiled as a result of the consultation findings (see section 4 and Appendix 3) could be developed for use within NHS Board, Community Health Partnership (CHP) or local authority areas to help meet this need.

Practical help

3.11 The majority of people with conditions other than cancer and informal carers who responded to consultation told us that they felt that the amount of help they received was in accordance with their wishes. However, these groups also identified some barriers to accessing practical help.

Barriers to practical help: assessment

3.12 The need for regular assessments of the needs of people with life-threatening conditions other than cancer was recognised by all groups in the consultation. The uncertain disease trajectory, fluctuating symptoms and rapid deterioration seen in many conditions other than cancer means that regular assessments are needed to ensure that people with these conditions are in receipt of appropriate services, equipment and adaptations and their informal carers are given an appropriate level of support. Some respondents in the consultation told us that they were not receiving regular assessments/reviews.

> 'We have only seen a neurologist 3 times since 1988.'
>
> husband of a lady with multiple sclerosis

Overcoming barriers to practical help: assessment

3.13 Regular reviews allow for the early identification of people's needs and therefore the opportunity to provide services to meet those needs. This, coupled with anticipatory care, should ensure people's needs are met amidst the challenge of fluctuating symptoms and/or rapid deterioration. This is already working well for some people:

> 'We have been fully supported and at times have been quite surprised by the things that have been suggested in advance of their being proved necessary.'
>
> husband of a lady with motor neurone disease

3.14 Many respondents suggested that a key worker should be available to all people with conditions other than cancer. The aim of this role would be to ensure a regular assessment of needs, to co-ordinate appropriate services to meet the assessed needs and to prevent duplication.

> 'Patients with end stage motor neurone disease/multiple sclerosis would benefit from a key worker system to co-ordinate care. Patients are exceptionally vulnerable at this time. Palliative care support can be invaluable.'
>
> occupational therapist

Barriers to practical help: access to services

3.15 Several respondents told us that they had come into contact with an individual professional who had been able to direct them to services of which they were previously unaware. Whilst this had a positive impact on individual respondents, it highlighted a lack of consistency in the provision of services.

> 'We got more help when we got a good social worker, so one good person made a massive difference. If she hadn't come along, we wouldn't have got half the benefits or other things (washing machine, telephone) that we have now.'
>
> husband of a lady with Parkinson's disease

3.16 Other respondents told us that since services were not immediately available to them, they had to invest time and effort gaining access to them.

> 'Help should be available to everyone and should be easy to access. I got help eventually because I'm an intelligent, articulate person who was willing to lobby SEHD and local council until I got the appropriate treatment and my specialist was the same. Without this, it would be very easy to slip through the net and not get any help.'
>
> gentleman with heart failure

3.17 Some of the people with conditions other than cancer and informal carers who responded to the consultation told us that they were not aware of the availability of general help (ie general household tasks including basic household maintenance). Respondents saw this as a very important area and found it distressing when general household chores were not done. Some respondents told us that general help was available but was not a financially viable option.

> 'I would like help with household chores but I know to get this the last quote I had from social work was £280 per month as I am 51 years old and I don't qualify for free care.'
>
> lady with motor neurone disease

3.18 Health and social care professionals identified a lack of an intermediate level of care for people who have significant needs but do not need an in-patient bed in an acute hospital or a hospice.

3.19 Another barrier to availability of services was the length of time taken between requesting and receiving services. This was recognised by all consultation groups, and NHS Boards told us that a key issue for them was the challenge of developing services which are responsive to urgent and changing needs when implementing palliative care strategies. This was also an issue for people who had conditions that take a significant length of time to diagnose and/or whose condition was marked by a rapid deterioration.

> 'NHS and social services – the process is too slow. Direct payments took 11 months from initial contact to employing a carer.'
>
> gentleman with multiple sclerosis

3.20 A further issue identified as a barrier by respondents from NHS Boards and voluntary organisations was the inappropriate location of services.

> 'Over 90% of the expertise is within the acute hospital and over 90% of the need is in the community.'
>
> Dumfries and Galloway Council

3.21 A recurring theme amongst people with conditions other than cancer and informal carers was difficulty in accepting some of the available help. This applied particularly to help with personal care and respite care. It is known that expectations are low in this group and this was borne out by the carers who told us that they felt they should carry out all the care required unaided.

> 'You want to think you can do all the caring yourself and it doesn't seem right for someone else to be looking after your husband. I worried what people would say. In the end I was just getting too tired and the practice nurse saw it and encouraged me to get help in.'
>
> wife of a gentleman with dementia

Overcoming barriers to practical help: access to services

3.22 Providers of specialist palliative care suggested that an evidence base of palliative care needs could be established to allow for the development of strategies to meet the identified needs.

> ‘More research into palliative care is essential. This can be difficult in a patient group where time is limited and ability to take part may be compromised. But, combined research with involvement from several units and representatives from a range of incurable illnesses could establish the needs of a patient population. The pathway from an acute phase of the illness into a palliative phase could be identified – so that from diagnosis onwards these patients are assured of care.’
>
> senior physiotherapist, hospice day services

3.23 Barriers to consistency in the help available to people with conditions other than cancer and informal carers can be overcome through the provision of information about appropriate, locally available services. This would increase awareness of local services in people with conditions other than cancer, informal carers and the health and social care professionals involved in their care, and lead to increased and more consistent access to appropriate services.

3.24 Generic health and social care professionals were asked about the kind of palliative care support that would most benefit the people they cared for. They identified user and carers involvement, appropriate respite and outreach support as priorities.

3.25 NHS Boards and local authorities have already done much work to address the barriers identified and it is clear from the consultation that further work is planned in this area.

> ‘In terms of increasing our efforts to keep people who do not need hospital care in the community it is crucial that we start to focus on the palliative care needs of people with other long term conditions. It is a quality of life issue.’
>
> Aberdeen City Council

3.26 Some areas have developed services based on recognition of the needs of these groups.

> 'We have developed a crisis/rapid response service that can support people at home at very short notice, or assist to expedite discharge from hospital earlier than ever before. Non-malignant palliative care patients have benefited greatly from this approach according to feedback we have received from patients, carers and professionals'
>
> Falkirk Council

> 'We take a person-centred approach to the assessment of individual service users using single shared assessment and provide a range of flexible, needs led support services depending on individual need. We aim to assist people to achieve their wishes of staying in their own homes for as long as it is safe and practical to do so; we therefore provide services regardless of specific diagnosis.'
>
> East Ayrshire Council

3.27 Consultation respondents suggested that people of all ages with conditions other than cancer should be given funding for help with general household tasks. Providers of specialist palliative care also stressed the importance of the contribution of volunteers in the palliative care setting.

> 'I think it is important to be aware of the importance of the role of the volunteer team in the palliative care setting. Our volunteers are an invaluable resource providing transport, complementary therapies, befriending, general support etc. Definitely a collective group to be given real consideration in any palliative care discussions.'
>
> volunteer services manager, hospice

Barriers to practical help: equipment and adaptations

3.28 People with rapidly progressing or fluctuating conditions have a need for timely access to equipment and adaptations. The adaptation that was most wanted by people with conditions other than cancer was an adapted bathroom and the pieces of equipment that were most wanted by people of this group were a hoist and an aid to pick things up off the floor.

3.29 People with conditions other than cancer, informal carers and health and social care professionals identified lack of priority and lack of joint working as the main barriers to receiving appropriate equipment and adaptations. This results in people receiving equipment and adaptations long after they had been assessed as needing them and can use them.

3.30 NHS Boards and local authorities also recognised the challenges of meeting the need for equipment and adaptations in a timely fashion.

> 'There is a view that those at the end of their life should receive very speedy social and healthcare responses to enable them to die at home if that is their wish. Arranging stair lifts etc is obviously more difficult in a short period of time.'
>
> NHS Lanarkshire

Overcoming barriers to practical help: equipment and adaptations

3.31 Many respondents highlighted the need for a fast track system for people with conditions which are characterised by rapid deterioration. In this way, equipment and adaptations could be provided in time for them to be of use.

Barriers to practical help: financial matters for patients and carers

3.32 Financial constraints were a deciding factor in whether or not people asked for the level of care they required.

> 'We have to pay for personal care. If that were not the case I would like more – in fact I need more.'
>
> lady with multiple sclerosis

3.33 The age of some respondents living with a condition other than cancer was also a barrier. Many respondents were too young to qualify for free personal care (available to people aged 65 or over who are assessed as having a need). This, combined with the fact that respondents (and possibly their carers) had had to reduce their working hours or stop working, made their financial position very difficult.

> 'Because of his age he's not entitled to disability and mobility allowance and so I just get attendance allowance. If I hadn't given up work it would have cost them a lot more to provide care for him.'
>
> mother of a son with muscular dystrophy

> 'Having to be in a wheelchair 24/7 I get very cold and need more heating in winter. Old people get a couple of hundred pounds in winter to help with heating and things. What about us disabled folk?'
>
> lady with multiple sclerosis

Overcoming barriers to practical help: financial matters for patients and carers

3.34 Respondents suggested that people living with a non-malignant condition should be given access to free personal care and heating allowance. This would reduce the financial inequity experienced by people with conditions other than cancer.

> 'One of the problems is that, as a middle aged person with a chronic progressive disability, my husband is not on anyone's radar so receives less help as a right than a child or a pensioner. What is needed is to sweep away the whole shabby structure of support based on age and means testing, which forces us to beg (often unsuccessfully) for things that others get as a right, and replace it by support based on clinical need.'
>
> wife of a gentleman with multiple sclerosis

Barriers to practical help: financial matters for service providers

3.35 Resource constraints were identified as a barrier by generic health and social care professionals and providers of specialist palliative care. NHS Boards identified competing priorities for funding as an issue in implementing palliative care strategies for people with malignant and non-malignant conditions. Ensuring sufficient capacity in community teams was also identified as a challenge by local authorities.

> 'There are often differences in priorities for funding in the health and social service sectors and also differences in priorities among the three local authorities within the single Health Board area.'
>
> NHS Ayrshire and Arran

Barriers to practical help: respite care

3.36 Informal carers, health and social care professionals and voluntary organisations identified a lack of availability of suitable respite services for young adults and people with challenging behaviours as a barrier to practical help.

3.37 A small number of respondents told us that they felt that barriers were imposed by professionals.

> 'If I ring up and ask for respite, I get told there is none. So I ring round and book my husband in for respite myself and then call the social worker back with the details so they can fund it. They should do that. I shouldn't have to do it.'
>
> wife of a gentleman with dementia

3.38 Some respondents were reluctant to access respite care following a bad experience. In other instances the person with the condition and/or the carer felt that other people would not be able to provide care of the same standard as the informal carer. This mainly related to personal care, but also included some condition-specific issues eg the difficulty in leaving children with cystic fibrosis with other people because of the need for physiotherapy.

Overcoming barriers to practical help: respite care

3.39 Several respondents identified day centres as positive services providing social opportunities for people with conditions other than cancer and a break from caring for their informal carers.

> 'I feel very strongly that day centres should be made available for people with chronic illnesses who are being cared for at home… it would benefit both the person with the condition and the carer if they could be given a break from each other… it could reduce the need to book the patient into respite care on a regular basis.'
>
> gentleman with heart failure

3.40 Shorter, but regular, periods of respite were seen as positive by carers, as this allowed them to continue with their routine tasks as well as having some time to socialise. This enabled them to cope with their caring role and in some instances to care for their relative at home for longer.

> 'Alzheimer Scotland provide day care and in house caring for 3 half-days per week which allows me to shop, socialise, pay bills etc. It also provides my husband with social interaction and stimulation… this resource has been invaluable in allowing my husband to continue to live at home.'
>
> wife of a gentleman with dementia

3.41 Carers also told us that flexibility in the availability of respite care would help them to organise some social activities for themselves when the person they cared for went for respite care. This could be achieved if the timing of respite care could be negotiated with those providing it.

> 'I wish the system could be more flexible. My wife goes for respite every six to eight weeks and I've tried to get it arranged so it's as often as she needs it and it coincides with when I go away but that's really frowned upon and they won't bend the rules at all. They just say she has to go on the dates they tell us. We get 8 weeks notice and that's not long enough for me to sort something out.'
>
> husband of a lady with multiple sclerosis

3.42 Parents of children with conditions other than cancer told us that they were particularly grateful for the respite care provided by children's hospices, as they knew that their children were being cared for by people they trusted.

> 'We get respite 3 weeks a year at the children's hospice. We go as well and we feel we have had a break but we're still with him. The thing about the children's hospice is that it's somewhere he can go where I know they look after him and love him like I do.'
>
> mother of a child with cystic fibrosis

Barriers to practical help: support for carers

3.43 The majority of informal carers who responded to our consultation told us that they felt that their own health had been affected as a result of the time they had spent caring. Most of the informal carers said that they had been able to discuss this with someone. Most also told us that they had only a few hours a week to carry out activities apart from their caring role and so this group may have little time to ask for help.

Overcoming barriers to practical help: support for carers

3.44 Members of the user reference group have suggested that informal carers should be encouraged to have a carers assessment and to inform their GP of their caring role. Their GP notes should also be 'flagged' to denote this role. These areas have all been included in the information support checklist which has been developed as an outcome of this project and is recommended for use (see section 4 and Appendix 3). The use of the information support checklist would also help to ensure that people with conditions other than cancer and informal carers are made aware of and have access to the help available to them, including carers assessments.

Barriers to practical help: geographical barriers

3.45 People with conditions other than cancer and informal carers told us that the challenges of living with such a condition in remote and/or rural areas was a barrier to accessing help and support.

> 'I don't see a specialist where I live because there isn't one available. I have to travel a long way if I'm ill and need the specialist for my condition.'
>
> young adult with cystic fibrosis

3.46 The impact of the distances involved in working in geographically remote areas was also identified as a barrier by some health and social care professionals, NHS Boards and local authorities. Distance was seen by some as a barrier to spending as much time as was needed clinically as so much time was taken up by travelling. Remoteness and rurality also had an effect on professional support. Many professionals were lone workers who told us their roles could be isolating.

3.47 Planners also highlighted the challenge of providing appropriate care across a large geographical area.

> 'Enabling equity of provision across a diverse, rural, geographical area where deprivation is more prevalent in particular areas is a key issue.'
>
> Aberdeenshire Council

Overcoming barriers to practical help: geographical barriers

3.48 Generic health and social care professionals working in remote areas use telelinks, and in some cases telemedicine to help them to overcome geographical barriers. Some consultation respondents suggested an outreach service from specialist palliative care to overcome the barriers caused by their geographical isolation.

> 'The hospice consultant could visit the island on a regular basis to provide education to GPs and nurses and to assess and advise on complex cases.'
>
> district nursing sister, remote community

3.49 Others suggested enhancing the knowledge of specific generic health and social care professionals.

> 'Due to rurality inequity occurs. Perhaps nominated practitioners with enhanced knowledge could minimise this.'
>
> community nurse, island community

3.50 Some consultation respondents had developed ways of overcoming geographical barriers to meet the needs of their patients:

> 'A care pathway has been piloted to ensure the more remote areas can access appropriate levels of care.'
>
> Orkney Islands Council

Practical help: recommendations 2-7

Recommendation 2: regular assessment

Regular assessments by members of a multi-disciplinary care team should be available to people with life threatening conditions other than cancer and their informal carers to ensure that complex and frequently changing needs are recognised and met and that appropriate and timely practical help is available.

Recommendation 3: care management

The care management of people with progressive non-malignant conditions should be undertaken by an appropriate key health or social care professional responsible for streamlining individual care, co-ordinating a multidisciplinary approach, preventing duplication and enabling faster access to services.

Recommendation 4: flexible service delivery

Services for people with non-malignant conditions should be developed with meaningful user and carer involvement, facilitated and supported as appropriate, and provided in a flexible manner to meet individual and changing needs. Consideration should be given, for example, to appropriate timing of out-patient appointments and home care visits.

Recommendation 5: respite care

Respite care should be available to people with progressive non-malignant conditions in settings appropriate to their age. Such facilities should have access to the expertise of condition-specific specialists to ensure that all staff involved have an understanding of the condition and how it affects the individual concerned.

Recommendation 6: equipment and adaptations

Consideration should be given to the provision of a fast track service for the provision of equipment and adaptations, including wheelchairs, for all people with progressive life-threatening conditions who have rapidly changing needs.

Recommendation 7: financial help

Consideration should be given to the provision of benefits such as free personal care, heating allowance and funding for general household chores for people with progressive conditions other than cancer who are under 65 years of age and who have been assessed as having a need for these services.

Symptom management

3.51 Approximately half of the people with conditions other than cancer and informal carers who responded to consultation said that they/the person they cared for did not need further help with symptom management.

3.52 All groups questioned, however, recognised the difficulties posed by the need for symptom management over long periods of time and through unpredictable disease trajectories, and in particular the challenges presented by communication and/or cognitive difficulties.

3.53 Barriers to optimum symptom management identified by some consultation respondents were:

- lack of collaborative working
- lack of regular review
- inadequate administration of medications.

Optimum symptom management barriers: lack of collaborative working

3.54 Some people with conditions other than cancer had experienced an unco-ordinated approach by the professionals involved in their care.

> 'Doctors don't seem to communicate at all. One of them will start me on a new medication and another will say 'Why are you taking that?'.'
>
> gentleman with heart failure

3.55 Professionals identified a lack of awareness of available drugs and a lack of recognition of symptoms as a barrier to people with conditions other than cancer receiving appropriate symptom management.

> 'There is a lack of awareness of use of drugs to alleviate respiratory symptoms and a reluctance generally to try to alleviate them.'
>
> respiratory clinical nurse specialist

> 'The health community in general does not acknowledge palliative care needs for people with dementia. Pain can be overlooked.'
>
> consultant psychiatrist, older adults

3.56 Consultation respondents told us that a further barrier was created where generic health and social care professionals did not access colleagues in specialist palliative care for symptom management advice.

Optimum symptom management barriers: lack of regular review

3.57 Many non-malignant conditions are characterised by rapidly changing symptoms and a rapidly deteriorating and/or fluctuating physical condition. People with conditions other than cancer and informal carers identified a lack of regular review as a barrier to effective symptom management and therefore a barrier to people with conditions other than cancer achieving an appropriate level of care and an optimum quality of life.

> 'The GP came out when we called him because my husband was unwell and he asked my husband how his walking was. He hadn't been able to walk for months. I think the GP was very shocked when he saw him. He offered us lots of help then. If we hadn't happened to call him out that wouldn't have happened.'
>
> wife of a gentleman with motor neurone disease

Optimum symptom management barriers: administration of medications

3.58 Informal carers recognised that the administration of medications can be challenging when a person has cognitive, communication or behavioural difficulties. However, some felt that more could be done to ensure that people received the medication that would alleviate their symptoms.

> 'I have found it very disturbing when told that my relative can refuse antibiotics, pain medication, etc. … I believe that at the first hint of refusal, the nurse can walk away, fully protected by the law. What about the patient's rights? This is a grey area. It is terrible to see and hear a relative in pain and be told 'he refused his meds'. Coaxing is the key.'
>
> daughter of a gentleman with dementia

Overcoming barriers to optimum symptom management

3.59 The development of a key worker role in the care management of people with conditions other than cancer would influence symptom management by ensuring effective collaborative working and improving consistency.

3.60 Increased awareness among generic health and social care professionals of the general palliative care needs of people with non-malignant conditions would highlight the need for symptom control, particularly in people with cognitive or communication difficulties who are less able to express those needs.

3.61 Enhanced opportunities for collaboration between health and social care professionals working in generic settings and those in specialist palliative care would raise awareness of available options in symptom management and optimise the care of those with complex needs.

Symptom management: recommendation 8

Recommendation 8: symptom management

Opportunities for collaboration between health and social care professionals working in generic settings and those in specialist palliative care should be enhanced wherever possible to ensure that optimum symptom control is available throughout the disease journey to all those with progressive non-malignant conditions.

Joint working

Barriers to joint working: patients and carers/health and social care professionals

3.62 All consultation groups recognised the importance of patients and carers working in partnership with professionals to ensure high quality, patient-focussed care. Patients and carers wanted to maintain good relationships with the health and social care professionals involved in their care and valued continuity of care. These groups saw frequent changes in health and social care professionals as a barrier to good care.

3.63 In some instances, people with conditions other than cancer and/or informal carers were not satisfied with the level of care received.

> 'My relative is already in care, but aspects of care leave much to be desired, therefore meetings, letters and research have to be done to ensure that care. … I feel that the professional carers themselves are not informed. Frequently my entreaties fall upon deaf ears so it is a repetition game.'
>
> daughter of a gentleman with dementia

3.64 Inflexibility in the timing of services was also seen as a barrier. Consultation respondents told us that people with conditions other than cancer often need more time to complete everyday tasks due to symptoms such as breathlessness, fatigue and reduced mobility. They and their carers did not feel that this was always recognised by professionals.

> 'The last appointment for the specialist is 10.30am. We haven't got a hope of having my husband up and ready by then, let alone at the hospital.'
>
> wife of a gentleman with motor neurone disease

> 'Carers come at a specific time to help people to get washed and dressed at 9.30am. People with chronic obstructive pulmonary disease take a while to get going and can't be rushed.'
>
> respiratory nurse clinical nurse specialist

3.65 The importance of the attitude of professional carers was also raised and there were some comments about the need for health and social care professionals to have the right personal attributes for their role.

> 'Some carers are functional. They do the job but they're not caring. You can't teach it to someone. It comes from within.'
>
> wife of a gentleman with dementia

> 'Professionals need to remember that they are guests going into someone's home.'
>
> wife of a gentleman with dementia

3.66 Many people with conditions other than cancer and informal carers told us that they felt fully involved with decisions made about their care and were kept well informed. Others, however, were not satisfied with their level of involvement or the level of collaboration between professionals.

> 'I was shown how to use a turning disc and subsequently our occupational therapist refused to let us have one on safety grounds. Not very joined up, was it?'
>
> partner of a lady with multiple sclerosis

3.67 NHS Boards identified difficulty achieving representative user involvement as a barrier to partnership working:

> 'One issue that does arise is that there is a wide range of groups with an interest in palliative care, and it is sometimes challenging to get a voice… which can be said to be truly representative of the constituency.'
>
> NHS Tayside

Overcoming barriers to joint working: patients and carers/health and social care professionals

3.68 The consultation highlighted examples of partnership working between people with conditions other than cancer and their informal carers and the health and social care professionals involved in their care.

> ‘I was asked about special things my husband needed, eg special diet etc I was definitely fully informed and involved and they did listen to what I said.’
>
> wife of a gentleman with dementia

3.69 However, some barriers were also identified. Carers told us that if they were listened to more by health and social carers, the needs of the person they cared for could be met more easily. This applies particularly when people with dementia are admitted to hospital, as informal carers can provide invaluable information about the care needs of their relative. Many carers are also keen to stay at the hospital and assist with the care given.

Barriers to joint working across different professions and care settings

3.70 The main barriers to joint working across different professional groups and care settings identified by the consultation respondents were:

- lack of joint planning between care settings
- lack of/late referral
- poor communication.

3.71 People with conditions other than cancer and informal carers told us that they were frustrated by poor communication when it occurred and some told us that where there were clear communication difficulties, their confidence in the professionals providing their health and social care was affected.

> ‘It would make a difference if professional staff working in different places communicated better and didn’t disagree with each other. I get stuck in the middle of what they say.’
>
> gentleman with heart failure

3.72 In some instances, poorly co-ordinated transition between different care settings, in particular between hospital and home, was identified as a barrier to people receiving appropriate care. Poor communication at the point of discharge from hospital was highlighted as a barrier by several respondents. Some respondents also identified a lack of integrated care pathways as a barrier in this area.

> ‘Communications between primary care and secondary care medical department are not good and patients are sent home several days before we receive communication regarding drugs etc and discharge letters.’
>
> general practitioner

3.73 Professionals also identified late referrals as a barrier to people receiving appropriate palliative care, as this resulted in people with conditions other than cancer not gaining timely access to professionals from different disciplines who could help with their symptom management.

> 'Often referrals are made too late. Many patients slip through the net and we often become involved far too late in the day. If I were referred the patient before they started having real problems we could monitor them much more appropriately. I recently had a lady with a non-malignant condition whose weight had plummeted to five stones before she was referred to me. This of course could have been prevented.'
>
> generic dietician

3.74 The lack of a key worker to co-ordinate care across professional groups and care settings was also highlighted as a barrier. Health and social care professionals and voluntary organisations identified a lack of leadership in care as a barrier.

> 'It's often difficult to identify who has the lead role and it must be difficult for the clients too.'
>
> occupational therapist

3.75 NHS Boards also told us about the challenge of providing equitable access to appropriate palliative care across a range of care settings.

> 'The key issue will be developing a model of palliative care that can offer patients equitable and appropriate care in a range of settings – community, care homes, community hospitals, acute hospitals and hospice, and for both malignant and non-malignant conditions.'
>
> NHS Forth Valley

> 'Improving communication across a broad range of services and ensuring appropriate access to specialist advice. This issue covers out of hours services, discharge planning, use of single shared assessment, provision within care homes and early referral/intervention principles.'
>
> NHS Greater Glasgow and Clyde

Overcoming barriers to joint working across different professions and care settings

3.76 When we asked informal carers what would help them to cope, one of the most common responses was 'doctors, nurses and others involved talking to each other and sharing information and records'.

3.77 Health and social care professionals told us that earlier referrals between professionals would allow for planned early input with people with conditions other than cancer before a crisis point was reached. Proactive working, rather than waiting for referrals, could also significantly reduce delays, provide more timely access to services and increase the level of confidence of people with conditions other than cancer and informal carers in the health and social care professionals involved in their care.

> 'Better interagency working particularly in relation to hospital discharge (primary care and wards often do not appear to communicate effectively). Protocol for discharges around the need for discharge meetings etc.'
>
> generic social worker

3.78 Some areas were developing integrated care pathways for use across care settings, or had groups which co-ordinate activities between care settings.

> 'Integrated care pathways for people with dementia are being developed. These will include pathways in and through palliative care. A plan encompassing all aspects of cardiac care is to be developed. It will include a section on palliative care.'
>
> NHS Dumfries and Galloway

> 'We have a primary care reference group, which acts as a strategy group. This group is multidisciplinary and cross references and cross reports on activities in the primary care setting.'
>
> NHS Grampian

Barriers to joint working: health/social care

3.79 In many areas health and social care professionals are already working together to deliver high standards of collaborative care. Ten of the twelve NHS Boards who responded to consultation told us that their current palliative care strategies specifically included the palliative care needs of people with life-threatening conditions other than cancer and had been developed in partnership with local authorities and voluntary organisations.

3.80 Representatives from NHS Boards, local authorities and voluntary organisations all identified a lack of understanding of palliative care as a barrier to the provision of appropriate palliative care for people with conditions other than cancer.

> ‘There is confusion about what palliative care is. Everyone seems to know the World Health Organization (WHO) definition but so often people are talking about late stage/end stage care.’
>
> director, voluntary organisation

3.81 NHS Boards and local authorities were asked to identify the barriers to bringing about increased collaboration between health and social care professionals. Both identified the same key areas:

- education and training
  - lack of training in the principles of palliative care
  - poor understanding of the need for palliative care

- joint working
  - lack of integration, collaborative working and information sharing
  - lack of recognition of the value of each other’s roles
  - poor communication channels between professionals and between patients and professionals
  - uncertainty about where roles and responsibilities lie and where gaps and overlaps exist

- organisational differences
  - challenging organisational planning and budgeting boundaries and processes
  - cultural differences between health and social care
  - different planning and funding cycles
  - different priorities between health and social care
  - different priorities between different local authorities within NHS Board areas

- resources
  - different finance channels
  - equipment and adaptations not being seen as a financially viable option
  - lack of knowledge of available resources
  - workload and resource implications, including lack of reflective time.

3.82 Local authority respondents told us that the needs of people with life-threatening conditions other than cancer represent one of a number of competing priorities. This group also told us that palliative care was seen as being concerned with meeting people's health care needs and not their social needs. The emphasis on a medical model of care was also seen as a barrier by this group to the provision of appropriate integrated health and social care. They also identified barriers with definitions related to existing Scottish Executive guidance, which could lead to confusion about whether care should be provided and/or funded by health or social care services.

> 'Palliative care planning is organised into Managed Clinical Networks which tend to emphasise the medical model and leave little room for social care and inclusion issues.'
>
> City of Glasgow Council

3.83 Local authorities also identified lack of clarity over the meaning of palliative care and what it involves as a barrier.

> 'Lack of appreciation from all sides about what might be included within palliative care, since a lot of work could fall within this description but is not called or thought of as palliative care. There is a belief, stemming to a large extent from continuing care guidance, that palliative care equates only to end of life care ie the last six months, and is therefore solely a health responsibility. Sometimes the barrier is funding and who should fund palliative care.'
>
> City of Edinburgh Council

3.84 Health and social care professionals working directly with both people with conditions other than cancer and informal carers also identified barriers to joint working. Many respondents identified the point of transfer between care settings as a time when joint working was problematic.

> 'Difficulties can arise at the point of discharge from hospital. Hospital staff, for example, are very reluctant to have discharge meetings.'
>
> generic social worker

Overcoming barriers to joint working: health/social care

3.85 Several NHS Boards identified existing good practice in collaborative working between health and social care. They told us that the separate finance and communication channels of the two organisations were a hindrance to further progression in this area. These respondents recognised that palliative care takes place across a range of different care settings.

> 'We have good working relationships with health care colleagues – we have an excellent working relationship with local GPs and community nurses. They can be contacted at any time if required and they support the care that residential staff give.'
>
> Western Isles Council

3.86 NHS Boards and local authorities told us of their intention to continue to build upon existing good practice.

> '…to design services in such a way that it is clear in advance what care people will receive and organise outputs from all professionals and agencies into delivering this. While services can be good, it is clear that for this patient group, often the package of care is only as good as the less effective or slowest part. Joint service planning and organisation needs to be improved.'
>
> NHS Tayside

3.87 Community Health Partnerships (CHPs) were seen by many respondents as the best vehicle for moving strategy forward to effect change. Respondents told us that CHPs provided an opportunity for a more joined up approach to palliative care and that their development plans would be the vehicles for addressing the identified barriers to the provision of appropriate palliative care for people with conditions other than cancer.

3.88 Some areas have already established mechanisms for joint working between health and social care.

> 'Palliative care operational group, demonstrating innovative working between the NHS, voluntary sector and local authority in planning community care for palliative care patients. The group will be working to expand its remit to people with non-malignant conditions.'
>
> NHS Borders

> 'Aberdeenshire joint health and community teams have been in existence for over two years as part of our joint futures developments… and have built a strong tradition of collaborative working. They work with older people and adults with physical disabilities and chronic conditions, using single shared assessment, care planning folders and regular team meetings to share information and care plans for complex cases.'
>
> Aberdeenshire Council

3.89 Suggestions made by local authorities in our consultation to overcome the barriers to joint working were:

- a review of current guidelines to incorporate the national practice statements for general palliative care in care homes
- funding for additional hours to care for someone who is dying
- pooling of resources
- use of generic working.

3.90 In addition, clarity of purpose was seen as a way of overcoming barriers, so that all involved in the care were working to the same goal.

> 'Better and more proactive communication and sharing of information regarding the aims of patient care between professionals as well as enhanced understanding of the roles and responsibilities between statutory and voluntary agencies.'
>
> East Dunbartonshire Council

3.91 NHS Boards and local authorities identified the use of integrated care pathways between professional groups and care settings, joint protocols and joint prioritisation exercises as ways of overcoming the barriers

Barriers to joint working: access to specialist palliative care

3.92 The vast majority of generic health and social care professionals who responded to consultation told us that they felt that providers of specialist palliative care worked in collaboration with them to meet the needs of patients in their care. The barriers to providing appropriate palliative care identified by this group were:

- inadequate condition-specific knowledge
- inadequate knowledge of palliative care
- insufficient resources
- lack of clarity about how to access specialist palliative care
- lack of understanding of palliative care by people with conditions other than cancer and informal carers
- poor communication.

3.93 Providers of specialist palliative care were asked to identify what they thought were the current barriers to people with conditions other than cancer accessing specialist palliative care. The key barriers identified were:

- belief by the public and health and social care professionals that palliative care is only for people with cancer
- lack of awareness amongst professionals that their patients have palliative care needs
- lack of awareness of how to access palliative care
- lack of understanding of the nature of palliative care.

Other reasons given included:

- condition-specific teams may already be delivering palliative care effectively and have skills in managing symptoms commonly found in their patients
- insufficient resources (beds, funding, staff)
- reluctance on the part of generic health and social care professionals to discuss death and dying with their patients or to stop active treatment
- resistance/fear of hospice care on the part of patients and families.

3.94 The findings of the consultation showed that the key perceived barriers to the provision of specialist palliative care for people with conditions other than cancer are:

- lack of condition-specific knowledge on the part of providers of specialist palliative care
- inadequate knowledge of palliative care on the part of generic health and social care professionals
- insufficient resources
- inadequate referral and acceptance criteria
- lack of understanding of palliative care on the part of patients and carers
- poor communication.

Access to specialist palliative care: lack of condition-specific knowledge

3.95 Lack of knowledge of life-threatening conditions other than cancer was seen as a barrier to care provision by many providers of specialist palliative care, who felt that patients referred to them would expect them to have an understanding of their condition. Providers of specialist palliative care explained why they thought people with non-malignant conditions may not currently be referred:

> ‘Failure to inform other disciplines of my willingness to do so for fear of being inundated with conditions I don’t have enough knowledge about.’
>
> community Macmillan clinical nurse specialist

3.96 People with conditions other than cancer also saw a lack of condition-specific knowledge by the professionals involved in their care as a barrier to receiving appropriate care.

> ‘The nurses in the hospice are wonderful – very special people. But they don’t understand my condition and didn’t know what to do when I suddenly became unwell.’
>
> gentleman with heart failure

Access to specialist palliative care: knowledge of palliative care

3.97 There was also concern that some generic health and social care professionals may not be adequately skilled to provide general palliative care.

> ‘Sometimes concerned that in the eagerness to nurse complex palliative care cases in the community, there may not be adequate knowledge, skills and staffing levels to ensure the care is safe and sufficient to ensure a good death. Staff can be put in very difficult situations eg one district nurse from Friday night through until Monday morning.’
>
> district nursing sister

Access to specialist palliative care: capacity

3.98 Some providers of specialist palliative care told us that their current workload with cancer patients was too high for them to consider extending their service to people with conditions other than cancer.

> ‘I am not taking on too many non-malignant patients because of the long term impact on my workload. I may be able to manage when cancer caseload is small but not when more cancer patients are referred and I would not feel at liberty to discharge non-cancer patients.’
>
> community Macmillan clinical nurse specialist

3.99 Providers of specialist palliative care working within a hospice or day hospice setting recognised the complex needs of some people with conditions other than cancer. Where people had difficulties with mobility and communication, they often required significant nursing time and providers of specialist palliative care were concerned about the impact this may have on other patients.

> ‘Involvement with people with non-malignant conditions can have a major impact due to high dependency needs of the patients and their physical impairment. I think this can also have the potential to inhibit other patients if they perceive the nurses as ‘busy’.’
>
> day hospice sister

3.100 Many of the health and social care professionals who responded to consultation referred to the difference in services available to people with malignant conditions and those with non-malignant conditions. Several reasons were given for this. Some of the funding for hospices is from charitable cancer money and there are clear criteria for the proportion of people with non-malignant conditions who can be seen. In addition, the unpredictable nature of the disease trajectory and fluctuating symptoms experienced by many people with conditions other than cancer were seen as a challenge by service providers. Both generic health and social care professionals and providers of specialist palliative care told us that they were concerned about the inequity of service provision for people with conditions other than cancer who have palliative care needs which may continue over a period of many years.

> 'It is difficult to access equipment, respite care and alternative therapy for my group of patients but patients in the palliative stage of cancer are more able to access them. It just seems unfair/unjust.'
>
> clinical nurse specialist, Parkinson's disease

3.101 Several providers of specialist palliative care told us that they do provide a service to people with non-malignant conditions. However, many of these providers had concerns about the potential impact this may have on their workload and as a consequence this was not a service that was made readily available.

> 'Currently a third of my caseload is non-malignant. This is not, however, widely advertised. If this were the case, the impact would be much increased involvement.'
>
> Macmillan clinical nurse specialist, lymphoedema

Access to specialist palliative care: referral and acceptance criteria

3.102 Generic health and social care professionals identified a lack of consistency regarding referral and acceptance criteria for specialist palliative care as a barrier to people with conditions other than cancer receiving specialist palliative care when appropriate. Whilst the majority of this group told us that they knew how to make a referral to their colleagues in specialist palliative care, few respondents used formal criteria to do this.

3.103 Generic health and social care professionals involved with some patient groups found that there were restrictions on the people who could access in-patient hospice beds or day hospices. This was particularly so in the case of people with HIV/AIDS and/or those with a behavioural element to their condition.

> ‘Although hospices are willing to take people with HIV/AIDS, they will not take people with behavioural difficulties (a high percentage of our client group).’
>
> director, voluntary organisation

Access to specialist palliative care: patients’ and carers’ understanding of palliative care

3.104 NHS Boards identified a lack of understanding of what is meant by palliative care and who it should be available to as a barrier to the provision of appropriate palliative care for people with life-threatening conditions other than cancer.

3.105 Professionals also highlighted the lack of understanding of terminology used as a possible barrier to people with conditions other than cancer and informal carers accepting help.

> ‘Patients and carers don’t realise that there is a difference between palliative care and terminal care. They are often scared to tap into services available because of misconception.’
>
> generic physiotherapist

3.106 Several respondents to the consultation with providers of specialist palliative care also identified a lack of understanding of the role of specialist palliative care and a fear of hospices as a barrier to people with conditions other than cancer accepting a referral to specialist palliative care.

3.107 NHS Boards also identified the need for an understanding of palliative care for people with non-malignant conditions.

> ‘In implementing the non-malignant aspect we need to ensure that this culture is clearly understood.’
>
> NHS Lothian

Access to specialist palliative care: communication

3.108 Communication difficulties were identified as a further barrier to joint working between generic health and social care professionals and providers of specialist palliative care:

> ‘In renal medicine we often have a long relationship with the patient and family and they look to the renal team for everything, especially as we often see them three times per week. When they decide to stop dialysis and are dying, they will often die very quickly so it is

> important that we stay involved right to the end. When we do need to involve other specialists it is important that we know all decisions discussed/made as the patients/carers will always still come back to us for clarification/questions.'
>
> associate specialist in nephrology

Overcoming barriers to joint working: access to specialist palliative care

3.109 Generic health and social care professionals all identified the same model of care as the best way of meeting the palliative care needs of people with life-threatening conditions other than cancer. They wanted to maintain the working relationship they had developed, often over a period of years, with the person with the non-malignant condition.

> 'Many district nurses have a wealth of experience and this should be built upon and not produce teams that will suddenly take over our remit. Please allow us to continue to care for our patients.'
>
> district nursing sister

3.110 Providers of specialist palliative care also felt that the general palliative care needs of people with conditions other than cancer should be met by generic health and social care professionals, who should retain responsibility for individual patients. Providers of specialist palliative care felt that they should provide an appropriate level of input for people with complex needs.

> 'It would be more useful to act as a specialist resource rather than being expected to take on ongoing support for patients. Aim in the future would be for care to be continued to the end of life by the same professionals.'
>
> community palliative care clinical nurse specialist

> 'Many of the patients with non-malignant (and malignant) conditions have relatively basic palliative care needs and we therefore need to ensure that other professionals are providing this and so the Gold Standards Framework is a very positive move in this direction. We need to look at improving the level of general palliative care. This would then also free us up to be involved with patients with more complex symptoms and problems.'
>
> specialist registrar in palliative medicine

3.111 Providers of specialist palliative care recognised the need for clear routes of access to their services for generic health and social care professionals. Some hospices and specialist palliative care units already had referral criteria and others were developing these.

> 'Clear guidelines, agreed at local level. Thus both referrer and specialist palliative care are aware of the expectations ie scope and limitations.'
>
> hospice physician

3.112 It is clear from the consultation that a better understanding of the principles of palliative care and the palliative care needs of people with conditions other than cancer is needed. This can be achieved through education and training, the use of a palliative approach for all people with conditions other than cancer and joint working between generic health and social care professionals and providers of specialist palliative care.

> 'Palliative care workers need to work closely with the professionals who may have known the patient through most of their journey. Palliative care needs to be integrated into care and not just seen as an end stage solution.'
>
> speech and language therapist

3.113 Providers of specialist palliative care were keen to work jointly with generic health and social care professionals, particularly condition-specific teams.

> 'It is important to be able to access condition-specific specialist nurses to get the background knowledge about the condition. It may contribute to the reasons for symptoms and therefore the best ways to treat the symptoms.'
>
> community palliative care clinical nurse specialist

3.114 Consultation respondents told us that the needs of people with conditions other than cancer are being included in strategies and working groups.

> 'The palliative care strategy is a multi-agency strategy and includes the palliative care needs of people with non-malignant conditions.'
>
> NHS Forth Valley

> 'The palliative care specialty liaison group remit is already being widened to encompass non-cancer issues (specialist and generalist).'
>
> NHS Fife

3.115 We asked providers of specialist palliative care how increasing access to specialist palliative care for people with conditions other than cancer could best be managed. The most common responses were:

- education by multi-professional providers of specialist palliative care for members of condition-specific teams
- increased level of general palliative care skills amongst generalists, with specialist palliative care providing support and advice and concentrating on people with the most complex needs
- increased resources (beds, funding, staff)
- integrated care pathways/referral criteria/admission and discharge criteria
- joint working with condition-specific teams between health and social care and between acute and primary care
- promotion of palliative care as a specialty.

Barriers to joint working: paediatric and adult services

3.116 Parents who are carers can become physically and mentally exhausted as they become older and their children become more dependent and physically heavier to care for. Parents are trying to meet not only the increasing physical needs but the emotional needs of a child developing into a young adult.

3.117 The move from paediatric to adult services can be a difficult one as it is not always clear where referrals should be made to and in some instances, professionals in adult services may be unfamiliar with the condition the young adult has.

3.118 The needs and behaviour of young adults can sometimes be challenging for paediatric care settings. However, the alternative may be for young adults to be cared for alongside much older adults, with whom they have little in common.

> 'As a children's hospice we are able to meet the needs of children with non-malignant conditions. Sadly there are few if any appropriate resources in the community for young adults. Many have complex needs and resources tend to be for the older disabled person, without provision for younger service users.'
>
> social worker, family support, childrens hospice

3.119 A further barrier to good holistic care of young adults can be the lack of understanding on the part of professionals of how to relate to them.

> 'My daughter is not a baby – she is 17 years old.'
>
> mother of a daughter with cystic fibrosis

3.120 Frequent and/or prolonged periods of illness will prevent children and young people attending school or college and this may have a subsequent effect on their educational attainments and relationships with their peers.

Overcoming barriers to joint working; paediatric and adult services

3.121 The emphasis for children and young people should be on maintaining as normal a life as possible. Support, including the provision of appropriate equipment and effective symptom management, should be available to facilitate continuing access to education, contact with friends and participation in social activities.

3.122 The issue of transferring from paediatric to adult services has been addressed for young people with cystic fibrosis through development of a model of care which allows a gradual, managed transition over a period of two years, commencing at ages 13-14.

Joint working: recommendations 9-12

Recommendation 9: health and social care

The continued development of strategies and arrangements for effective joint working between health and social care agencies should be encouraged and supported. To further enhance an integrated approach to the care of people with progressive non-malignant conditions, NHS Boards and local authorities should collaborate to produce multi-professional and multi-agency directories of relevant local services (including condition-specific health care teams and social services teams) and to make updated versions of these available on an ongoing basis to staff in all care settings.

Recommendation 10: use of existing resources

The potential for more effective targeting and linkage of existing resources to meet the palliative care needs of people with progressive conditions other than cancer should be examined jointly by NHS Boards, Community Health Partnerships and local authorities.

Recommendation 11: preferred model of care

Steps should be taken to ensure that the preferred model of care which emerges from the consultation is available at the earliest possible opportunity to meet the palliative care needs of all on the basis of need not diagnosis:

- a palliative approach should be applied by generic health and social care professionals to the care of all patients with progressive life-threatening disease

- general palliative care should be provided for all those who need it by their usual health and social care professional team
- the provision of general palliative care by generic health and social care professionals should be enabled, facilitated and supported by appropriate input from providers of specialist palliative care
- the skills and resources of specialist palliative care should be targeted effectively towards those with both malignant and non-malignant disease who have complex palliative care needs
- overall responsibility for individual care should remain with the generic team.

Recommendation 12: specialist palliative care referral criteria

Hospices and specialist palliative care units should consider the implications for people with progressive non-malignant conditions when developing referral and admission criteria and should be explicit about the care they are and are not able to provide.

Psychosocial support

Barriers to psychosocial support: access to advice

3.123 The vast majority of people with conditions other than cancer who responded to the consultation said that they had the opportunity to ask questions and talk to someone who knew about their condition. However, fewer than half of the informal carers who responded told us that they had a similar opportunity to talk on their own to someone knowledgeable about caring for a person with this condition.

3.124 From the consultation responses it appears that the main barriers to informal carers receiving the advice they needed were:

- lack of information about the availability of advice
- lack of time to seek advice on the part of informal carers
- lack of time to provide advice on the part of professionals.

Overcoming barriers to psychosocial support: access to advice

3.125 It is known that the level of expectation in patients and carers is low and therefore one way of overcoming barriers is to raise the expectations of people with conditions other than cancer and informal carers. Information about carers assessments would help carers to understand that they are entitled to ask for help, and would give them license to ask.

3.126 The consultation also showed that there is a fear of palliative care amongst patients and carers, founded in a lack of understanding of what palliative care is and why it might be appropriate. Health and social care professionals suggested that this could be addressed by more open discussion and the giving of more detailed information.

> 'Information could be provided to all patients explaining that palliative care is not just for cancer so that the subject could be raised with them without provoking fear. They could then be informed of what care and support can be available to them in future and how to access this without feeling that a death sentence is being passed on them.'
>
> generic physiotherapist

Barriers to psychosocial support: emotional support

3.127 Several people with conditions other than cancer told us that they didn't feel that there was enough compassion shown towards them by some of the health and social care professionals involved in their care and by society as a whole. Many expressed the fear that they may be too dependent on one person.

> 'As I am totally dependent on my husband. I worry about what would happen if he were absent (ie died, took ill, got fed up with it all).'
>
> lady with multiple sclerosis

3.128 The consultation highlighted some barriers which were condition-specific. Many people with HIV/AIDS do not feel comfortable in disclosing their HIV status for fear of the reaction from family, friends, employers and colleagues and because of ongoing concerns about stigma and prejudice. The consultation also revealed the sense of isolation that people with cystic fibrosis can face as they are advised not to mix with others with cystic fibrosis due to the risk of spread of infection.

3.129 Some carers were members of carers support groups or panels and found this to be a very positive experience which helped them to maintain their caring role. Other carers had found meeting other people in the same position as themselves to be a negative experience.

> 'I went to meet other people in the same situation as myself, but it was all very negative and I came out feeling worse. I wanted to go somewhere where I would come out feeling uplifted.'
>
> wife of a gentleman with dementia

3.130 Some carers told us that they felt that they were exhausted as a result of their caring role and found it difficult to imagine getting any rest from it.

> ‘I will go on holiday for the first time without my husband this year and he’s going to go into a home for a week – I bet he’ll get worse just before I go.’
>
> wife of a gentleman with serious lung disease

3.131 Generic health and social care professionals told us that they felt there were barriers to people with conditions other than cancer and informal carers accessing services that would help to meet their psychosocial needs.

> ‘I sometimes encounter patients who would benefit from the emotional and psychological support offered by hospice admission but who are denied this because of long life expectancy and lack of symptom control problems.’
>
> consultant geriatrician

3.132 Providers of specialist palliative care told us that the inability to access specialist palliative care services was a barrier to people with conditions other than cancer being able to discuss death and dying.

> ‘Patients feel that they are unable to discuss their death and dying and what their wishes are. These are issues that tend not to be discussed when they are attending hospital. These patients often know they are dying but family/healthcare professionals are reluctant to discuss this.’
>
> community palliative care clinical nurse specialist

Overcoming barriers to psychosocial support: emotional support

3.133 People with conditions other than cancer and informal carers told us that they valued having the difficulty of their situation acknowledged.

> ‘It made a big difference to know we weren’t alone – there were people in the same boat and people who could help us.’
>
> husband of a lady with Parkinson’s disease

3.134 Several informal carers told us that they felt that more compassion would help them to cope with their situation.

> ‘Hospital carers having more sympathy and understanding of what carers are suffering.’
>
> wife of a gentleman with dementia

3.135 Several informal carers also told us that time to talk to someone who knew about the condition of the person they cared for without that person being present and having someone available on the end of the telephone for advice and support for them was very valuable.

Barriers to psychosocial support: respect for individuality

3.136 People with conditions other than cancer identified a lack of involvement in decisions about their care as a barrier to their individuality being respected.

> 'I'd like to be better informed and included in all aspects of my care, without just being told that a, b and c is going to happen.'
>
> lady with multiple sclerosis

Overcoming barriers to psychosocial support: respect for individuality

3.137 People with conditions other than cancer who responded to the consultation told us that they wanted to be involved in decisions about their care and to be recognised as an individual with their own personal needs.

> 'I want intelligent, empathetic answers to questions about my increasingly progressive illness. Knowledge of my disease by those people who work with me. Respect and acknowledgement of my individuality and needs. I want people to do things that help me to make sure I have good quality of life. I want my vulnerability recognised and respected and not used against me. I do not want to have things done to me. Behind my disability I have hopes and dreams and am a very positive person and do not indulge in neediness.'
>
> lady with multiple sclerosis

3.138 Informal carers also told us that they wanted to be allowed to make decisions about their caring role and that their choices need to be respected.

> 'I would emphasise that I think a patient should be allowed to be cared for at home for the absolute maximum time and carers allowed to decide themselves how they are managing to cope. In my opinion, they alone know if they can stand the pace.'
>
> wife of a gentleman with dementia

Barriers to psychosocial support: work and social activities

3.139 Another barrier to psychosocial wellbeing was loss of hobbies and interests. Restrictions to people with conditions other than cancer leading a social life and feeling in control of their lives were imposed both by the condition itself and by the care available. Respondents whose hobbies were mainly physical or sporting had had to give them up as their condition progressed. Some people were no longer able to read and/or write without assistance. Some told us that they found their condition depressing and lonely, they were able to do very little for themselves and they found some of their symptoms acutely embarrassing (eg tremor, muscle spasm, dribbling).

> 'More day centres should be made available for people with chronic illnesses who are being cared for at home. For those whose mental faculties are still intact but whose physical abilities are impaired, being stuck at home day in day out is a form of torture.'
>
> gentleman with heart failure

3.140 The majority of the informal carers who responded to the consultation told us that there had been a detrimental effect on their health as a direct result of being a carer. Many carers had had to reduce their working hours and social life and so had little social contact apart from the person they cared for and the health and social carers involved in their care. Informal carers told us that they tried hard to maintain as much as possible of the lifestyle that they and the person they cared for had prior to developing the condition.

> 'Trying to treat my husband as if he is still in control of the household ie what to buy, how much money to take out of the bank, generally trying to give him the opportunity to be the head of the household which he always was before his illness.'
>
> wife of a gentleman with Parkinson's disease

3.141 The effect of a significantly reduced income also played a major part in determining the level of social life carers had and affected their general wellbeing.

> 'I had to give up work in 1998. I had to relocate to an area with cheaper housing remote from family and friends. Now unable to go out much due to deterioration in partners condition. Very little social life.'
>
> partner of a lady with dementia

Overcoming barriers to psychosocial support: work and social activities

3.142 People with conditions other than cancer and informal carers told us that they would like more flexibility in their options for working eg flexible working hours or part time working to enable them to continue to work for as long as was reasonable. Information for employers on the condition their employee had and how it affected them may help to facilitate this.

3.143 Many of the respondents had overcome the barriers to social activities by choosing local activities/events that the person they cared for could also attend.

> 'I take my wife with me to social events. We mostly go out in our village. I feel I have enough time to do the things I want to. She would have done the same for me.'
>
> husband of a lady with Parkinson's disease

Barriers to psychosocial support: support for professionals

3.144 Professional isolation was identified as a barrier to peer support for some professionals. Other barriers identified were lack of availability of support and time constraints.

Overcoming barriers to psychosocial support: support for professionals

3.145 Where generic health and social care professionals had access to joint working with providers of specialist palliative care, they told us that they felt well supported. This group also told us that they felt more confident in their role if they knew that they could contact someone with specialist palliative care/condition-specific experience.

> 'We have a lot of support here. If we need advice on palliative care issues we can ring the Macmillan GP or Macmillan nurses. We're 'a long way from anywhere' but most of the palliative care staff are used to giving telephone advice.'
>
> GP – island community

Psychosocial support: recommendations 13-15

Recommendation 13: psychosocial needs

Specialist palliative care support should be sought for people with progressive conditions other than cancer who have complex psychosocial needs whether or not they also have complex physical needs.

Recommendation 14: fear of palliative care

Health and social care professionals should address any fear and misunderstanding of palliative care among those with progressive conditions other than cancer and their carers by initiating open discussion and providing appropriate information and psychological support.

Recommendation 15: discussion of death and dying

People with non-malignant life-threatening conditions should have the same opportunities as those with cancer to discuss issues and care preferences concerning death and dying. Specialist palliative care support should be sought to facilitate this.

Education and training

Barriers to education and training: patients and carers

3.146 The main barrier to informal carers receiving training appears to be lack of availability. Almost half of the consultation respondents in this group told us that they had not received any advice or training on how to look after the person they cared for and the vast majority of these people said that they felt that they would find it useful to receive some training. However, some people who had received training didn't feel that it related to their situation.

> 'They taught me how to lift in an environment that was totally different from our house and with someone to help me. The whole point is that I'm on my own doing the lifting.'
>
> husband of a lady with multiple sclerosis

Overcoming barriers to education and training: patients and carers

3.147 The main areas covered in training that had been received by informal carers were:

- diet and feeding
- lifting
- physiotherapy.

3.148 Informal carers who responded to the consultation told us that there are some good examples of training available to carers.

> 'My brother-in-law was diagnosed with vascular dementia and I accompanied my sister to classes organised by Alzheimers Scotland – Action on Dementia and we both found the course excellent. It enabled us to care for her husband at home for a number of years.'
>
> sister-in-law of a gentleman with dementia

3.149 It was clear from our consultation that input regarding symptom management would also be useful in training for carers.

Barriers to education and training: generic health and social care professionals

3.150 The majority of generic health and social care professionals who responded to our consultation told us that they would have access to education/training in palliative care if they wished to attend it. Approximately half said that they would be given funding and study leave and approximately a quarter said that they would be given travel expenses for this. The main barriers to education/training in palliative care identified by this group were:

- cover/caseload pressures/lack of backfill
- distance/location/travel
- funding
- lack of time
- professional isolation.

3.151 Other barriers to generic health and social care professionals accessing palliative care education and training included competing priorities for learning and a lack of awareness of the appropriateness of general palliative care to their patients.

> 'I think that there is a general perception that palliative care relates to patients with cancer and that because of that perception if you don't work with cancer patients you would automatically dismiss training opportunities as not being relevant to your area of work.'
>
> senior occupational therapist working in a generic setting

3.152 NHS Boards that responded to our consultation told us of the challenge of maintaining education/training amongst staff.

> 'Maintaining a rolling programme of education throughout the region can be difficult.'
>
> NHS Dumfries and Galloway

Overcoming barriers to education and training: generic health and social care professionals

3.153 An outcome of the project is a study day developed to address the palliative care education and training needs identified during our consultation with generic health and social care professionals (see section 4 and Appendix 2).

3.154 The project consultation showed that some areas had already developed training and identified the importance of this being continued.

> 'Good practical working relationships and collaboration within local services and good uptake of joint, multidisciplinary training need to be maintained.'
>
> NHS Shetland

3.155 In the consultation, providers of specialist palliative care recognised the importance of their role in the education and training of generic health and social care professionals.

> 'Through education we can directly influence the care of people with non-malignant conditions.'
>
> community nurse, specialist palliative care

Barriers to education and training: providers of specialist palliative care

3.156 Although we did not specifically ask providers of specialist palliative care about their education and training needs, many of the consultation respondents commented that they felt that a barrier to the provision of palliative care for people with conditions other than cancer was a lack of condition-specific knowledge. Providers of specialist palliative care told us that they felt that it was not possible for them to maintain expertise in every condition.

> 'We cannot be experts in every disease, therefore cannot know specifically how to care for every single person who needs specialist palliative care.'
>
> community palliative care clinical nurse specialist

Overcoming barriers to education and training: providers of specialist palliative care

3.157 The lack of condition-specific knowledge identified by providers of specialist palliative care can be overcome through joint working with condition-specific teams, with condition-specific teams providing general palliative care and maintaining responsibility for the patient and providers of specialist palliative care having input where appropriate for people with more complex needs.

Education and training: recommendations 16-18

Recommendation 16: training for informal carers

Consideration should be given by NHS Boards and local authorities to the provision of appropriate local training for informal carers including practical skills and guidance on symptom management.

Recommendation 17: palliative care education

The recognition of palliative care needs, the provision of general palliative care and when and how to access specialist palliative care support should be included in the basic training and continuing professional development of all health and social care professionals. The study day programme developed, piloted and evaluated during the project (see section 4 and Appendix 2) may be used as a template.

Recommendation 18: collaboration between health care teams

Enhanced opportunities for collaboration and the mutual sharing of knowledge and experience between condition-specific and specialist palliative care teams caring for people with progressive non-malignant conditions should be created wherever possible.

4

Project outcomes

4. Project outcomes

Palliative care study day

4.1 Although a range of palliative care educational provision is already available at various levels, it remains predominantly cancer-focused. While some providers have introduced educational interventions relating to conditions other than cancer, these remain few in number and awareness of their relevance is limited.

4.2 In response to the outcome of our consultation on the palliative care education needs of generic health and social care professionals, a palliative care study day was developed and piloted for this group.

4.3 The study day was aimed at multi-disciplinary groups of 15-25 health and social care professionals involved in the care of people with life-threatening conditions other than cancer in settings other than specialist palliative care. Analysis of consultation responses identified the greatest need for palliative care education and training among the following groups:

- allied health professionals
- care home staff
- home carers
- nurses
- social work staff.

4.4 The study day programme (see Appendix 2) was based on the learning priorities identified in consultation. The following areas were covered:

- understanding what we mean by palliative care
- recognising and meeting the palliative care needs of people with non-malignant conditions
- assessing and responding to some difficult symptoms
- assessing and responding to key issues towards the end of life
- understanding the patient's journey.

The methodology used was a combination of direct teaching, a participatory sculpting exercise and case study group work.

4.5 The study day was piloted in the spring and summer of 2006 to a total of 136 attendees from a range of professional groups and care settings in six venues across Scotland. Study days were held in Glasgow, Inverness, Dundee, Aberdeen, Edinburgh and Dumfries.

4.6 The study day was marketed using existing project contacts. Individuals and teams who worked in generic settings and were involved in the care of people with life-threatening conditions other than cancer were also targeted. This strategy was used because mass marketing and its subsequent demand for places could not be managed within the resources available to the project. Using the approach described, there was more demand for the study day than could be met.

4.7 Care was taken to ensure an even balance of professionals on each of the study days. Some prospective attendees were unsure of whether the study day was relevant to their needs and time was taken to discuss this with them on a one to one basis by telephone. This meant that recruitment of participants was time consuming. However, it was clear from subsequent evaluation that the even balance of professional groups attending contributed to the success of the study days.

4.8 Study day attendees were asked to complete a set of pre and post study day questions to evaluate any effect of their attendance on their understanding of palliative care.

4.9 The vast majority of study day attendees who completed the post study day questions told us that their understanding of the palliative care needs of people with life-threatening conditions other than cancer had changed as a result of their attendance at the study day.

> ‘Prior to the study day I would not have involved myself in discussions with patients and merely advised that another team would assist with their care. I feel more prepared to get involved now.’
>
> course participant (generic physiotherapist)

4.10 Attendance on the study day also led to recognition of the need to improve joint working between professional groups and care settings. Some attendees recognised that their profession was not as well understood as they had thought. This was apparent from comments made by participants about their experience on the study day.

> ‘The huge misunderstandings of the role of social workers came as a great surprise and this makes me feel social work needs to do something about this.’
>
> course participant (generic social worker)

> ‘Frustration at the vast chasm between ‘best practice’ and what can be done when each profession still works separately and sees their remit and care in a different way.’
>
> course participant (general speech and language therapist)

4.11 It is hoped that this study day will be of use beyond the life of the project to hospice and academic education departments engaged in the delivery of education in general palliative care and a palliative care approach. The full study day programme and details of each of the sessions are included in this report as Appendix 2. They can also be downloaded as a single item from the Partnership’s website on www.palliativecarescotland.org.uk

Information support checklist

4.12 A further outcome of the project was the development of an information support checklist (see Appendix 3) to help ensure that the information support needs of people with life-threatening conditions other than cancer are met.

4.13 The sources of information required to complete the checklist will vary between localities and will change over time. The checklist is therefore intended for use as a framework within NHS Board, Community Health Partnership and local authority areas to identify those responsible for ensuring the provision of information and to ensure that people living with life-threatening conditions other than cancer and informal carers within their area receive the information support they need.

4.14 The checklist is based on the information headings listed below, which were identified as priorities in consultation responses by people with conditions other than cancer and informal carers.

Benefits and financial matters

4.15 People with conditions other than cancer and informal carers told us that it was particularly important that they received information on how to access the financial help they were entitled to as early as possible.

Condition-specific information

4.16 Our consultation respondents told us that they need realistic information about the impact of their condition and its likely course, and that they want to receive this information from someone who understands the condition and has experience of caring for people with it.

Holidays and travel

4.17 People with conditions other than cancer and informal carers told us that they want to continue to travel and have holidays as much as possible. They identified the need for information to help them to make the most suitable arrangements for holidays and travel.

How to get extra help to give informal carers time off

4.18 People with conditions other than cancer and informal carers also told us that they need to know about the local services which may help to give informal carers time off and how these services can be accessed.

Where to find help, support and advice

4.19 Finally, people with conditions other than cancer and informal carers told us that available help, support and advice can be difficult to find. They identified the need for information to be provided which directs them to help, support and advice available to them in their local area, and tells them how to access more help as their needs increase.

4.20 The information support checklist is attached as Appendix 3. It can also be downloaded as a single item from the Partnership's website on www.palliativecarescotland.org.uk

5

Conclusions and recommendations

5. Conclusions and recommendations

Conclusions

5.1 The findings in this report support the steadily growing recognition that access to palliative care should be available on an equitable basis to everyone who is diagnosed with a progressive life-threatening condition. Since the inception of the project key policy developments and healthcare initiatives have continued to evolve in general acceptance of this stance.

5.2 *Delivering for Health*, published by the Scottish Executive in October 2005 in response to the Kerr Report *Building a Health Service Fit for the Future*, recognises the increasing incidence of long-term conditions as one of the main challenges facing the health service today. *Delivering for Health* sets out a vision for a model of care whereby people with long-term conditions are cared for in the community, without hospitalisation wherever possible, and with a shift from reactive episodic care to continuous support.

5.3 Many of the themes emerging from the project consultation exercise into the palliative care needs of people with progressive non-malignant conditions echo those of *Delivering for Health*. These include the need for:

- continuous, co-ordinated care provided locally in the community through integrated services and multidisciplinary working
- increased use of anticipatory care
- intensive care management for individuals with serious long term conditions
- stronger teamwork and greater collaboration and co-ordination between professionals and across organisational boundaries
- enhanced opportunities for closer integration of health and social services.

5.4 The project findings also accord with the responsibilities placed upon emerging Community Health Partnerships as a result of *Delivering for Health* regarding the management of long-term non-malignant conditions, and with the aims of the Care Management initiative of the Joint Future Unit to facilitate faster access to services and more targeted use of professional resources. *The Future Care of Older People in Scotland* (Scottish Executive 2006) places a parallel emphasis on the need for improved access to palliative care for all.

5.5 The Gold Standards Framework Scotland has over the past few years demonstrated the benefits in primary healthcare teams of identifying patients with palliative care needs and making simple improvements in planning and communication between health professionals better to meet those needs. The continuing roll out of this system in general practice and the inclusion of patients with conditions other than cancer in palliative care registers will contribute greatly to increasing access to palliative care for this group.

5.6 Finally, it has been clear that a greater understanding of the palliative care needs of people with non-malignant progressive conditions is required before detailed strategies can be developed. Many NHS Boards are already addressing this issue by including this patient group specifically in palliative care needs assessments.

Key messages

5.7 From the wealth of information gained through the project consultation process, some key messages therefore stand out. The first of these is that although there is a great deal here of which to take note, there are very few surprises. Most of what we have been told corroborates existing anecdotal evidence and expectations. It supports the existing policy framework and confirms that current developments are moving in the right general direction.

5.8 Secondly, the project findings provide reassurance that the aim of increasing access to palliative care for people with non-malignant conditions is achievable. There is evidence from many different sources that significant impact may be derived from relatively small changes to working practice, or from relatively small amendments to service design and delivery. And while even small changes are unlikely to be resource neutral, it is possible that many of the needs identified can be addressed with minimal resource implications. While both health and social needs are highlighted, consultation responses indicate that much could be achieved without making hugely unrealistic demands on already overstretched health and social care budgets.

5.9 Thirdly, it is clear from the evidence of the project consultation that many health and social care professionals are already working effectively together to deliver high quality, co-ordinated care to people with life-threatening conditions other than cancer. However, the consultation has also shown that professionals are often not aware of the range of services available in their area from which patients in their care could benefit and that the linkages and the flow of communication between services therefore require to be strengthened.

5.10 Fourthly, the preferred model of care which emerges by unanimous consent is one which builds on the existing expertise of all concerned, with overall responsibility for care, including general palliative care, remaining with the person's usual care team, and specialist palliative care support accessed when necessary for those with complex needs. The stated anxieties of condition-specific and primary healthcare teams that they would lose their close relationships with patients who had palliative care needs, and of specialist palliative care providers that they would be expected to assume overall responsibility for patients with conditions of which they had no detailed knowledge, would within this model be unfounded.

Recommendations

5.11 As a result of the project consultation findings, the following recommendations may be made. These appear in the same order as in the earlier sections of this report. The Scottish Partnership for Palliative Care believes that their implementation would make a meaningful contribution to improving access to palliative care for people with progressive life-threatening conditions other than cancer.

Recommendation 1: information support (p29)

Provision of information should be recognised as an important part of the proactive care of patients and carers. Steps should be taken to ensure that appropriate and locally relevant information is available to people with progressive non-malignant conditions and their informal carers from the point of diagnosis onwards. The information support checklist compiled as a result of the consultation findings (see section 4 and Appendix 3) could be developed for use within NHS Board, Community Health Partnership (CHP) or local authority areas to help meet this need.

Recommendation 2: regular assessment (p39)

Regular assessments by members of a multi-disciplinary care team should be available to people with life-threatening conditions other than cancer and their informal carers to ensure that complex and frequently changing needs are recognised and met and that appropriate and timely practical help is available.

Recommendation 3: care management (p39)

The care management of people with progressive non-malignant conditions should be undertaken by an appropriate key health or social care professional responsible for streamlining individual care, co-ordinating a multidisciplinary approach, preventing duplication and enabling faster access to services.

Recommendation 4: flexible service delivery (p39)

Services for people with non-malignant conditions should be developed with meaningful user and carer involvement, facilitated and supported as appropriate, and provided in a flexible manner to meet individual and changing needs. Consideration should be given, for example, to appropriate timing of outpatient appointments and home care visits.

Recommendation 5: respite care (p39)

Respite care should be available to people with progressive non-malignant conditions in settings appropriate to their age. Such facilities should have access to the expertise of condition-specific specialists to ensure that all staff involved have an understanding of the condition and how it affects the individual concerned.

Recommendation 6: equipment and adaptations (p39)

Consideration should be given to the provision of a fast track service for the provision of equipment and adaptations, including wheelchairs, for all people with progressive life-threatening conditions who have rapidly changing needs.

Recommendation 7: financial help (p39)

Consideration should be given to the provision of benefits such as free personal care, heating allowance and funding for general household chores for people with progressive conditions other than cancer who are under 65 years of age and who have been assessed as having a need for these services.

Recommendation 8: symptom management (p42)

Opportunities for collaboration between health and social care professionals working in generic settings and those in specialist palliative care should be enhanced wherever possible to ensure that optimum symptom control is available throughout the disease journey to all those with progressive non-malignant conditions.

Recommendation 9: health and social care (p58)

The continued development of strategies and arrangements for effective joint working between health and social care agencies should be encouraged and supported. To further enhance an integrated approach to the care of people with progressive non-malignant conditions, NHS Boards and local authorities should collaborate to produce multi-professional and multi-agency directories of relevant local services (including condition-specific health care teams and social services teams) and to make updated versions of these available on an ongoing basis to staff in all care settings.

Recommendation 10: use of existing resources (p58)

The potential for more effective targeting and linkage of existing resources to meet the palliative care needs of people with progressive conditions other than cancer should be examined jointly by NHS Boards, Community Health Partnerships and local authorities.

Recommendation 11: preferred model of care (p58)

Steps should be taken to ensure that the preferred model of care which emerges from the consultation is available at the earliest possible opportunity to meet the palliative care needs of all on the basis of need not diagnosis:

- a palliative approach should be applied by generic health and social care professionals to the care of all patients with progressive life-threatening disease
- general palliative care should be provided for all those who need it by their usual health and social care professional team
- the provision of general palliative care by generic health and social care professionals should be enabled, facilitated and supported by appropriate input from providers of specialist palliative care
- the skills and resources of specialist palliative care should be targeted effectively towards those with both malignant and non-malignant disease who have complex palliative care needs
- overall responsibility for individual care should remain with the generic team.

Recommendation 12: specialist palliative care referral criteria (p59)

Hospices and specialist palliative care units should consider the implications for people with progressive non-malignant conditions when developing referral and admission criteria and should be explicit about the care they are and are not able to provide.

Recommendation 13: psychosocial needs (p64)

Specialist palliative care support should be sought for people with progressive conditions other than cancer who have complex psychosocial needs whether or not they also have complex physical needs.

Recommendation 14: fear of palliative care (p64)

Health and social care professionals should address any fear and misunderstanding of palliative care among those with progressive conditions other than cancer and their carers by initiating open discussion and providing appropriate information and psychological support.

Recommendation 15: discussion of death and dying (p64)

People with non-malignant life-threatening conditions should have the same opportunities as those with cancer to discuss issues and care preferences concerning death and dying. Specialist palliative care support should be sought to facilitate this.

Recommendation 16: training for informal carers (p67)

Consideration should be given by NHS Boards and local authorities to the provision of appropriate local training for informal carers including practical skills and guidance on symptom management.

Recommendation 17: palliative care education (p67)

The recognition of palliative care needs, the provision of general palliative care and when and how to access specialist palliative care support should be included in the basic training and continuing professional development of all health and social care professionals. The study day programme developed, piloted and evaluated during the project (see section 4 and Appendix 2) may be used as a template.

Recommendation 18: collaboration between health care teams (p68)

Enhanced opportunities for collaboration and the mutual sharing of knowledge and experience between condition-specific and specialist palliative care teams caring for people with progressive non-malignant conditions should be created wherever possible.

Appendix I

Consultation questionnaires

Appendix 1: consultation questionnaires

Between autumn 2004 and spring 2006 postal questionnaires were distributed as part of our consultation process to:

- *people with life-threatening conditions other than cancer*
- *informal carers*
- *generic health and social care professionals*
- *providers of specialist palliative care*
- *NHS Boards*
- *local authorities*
- *voluntary organisations.*

Consultation was staged so that analysis of consultation with each group could be used to inform the content of consultation with subsequent groups. The majority of the consultation process was carried out via written questionnaires with freepost envelopes provided for reply. Questionnaires were developed by the project steering group with input from the professional and user reference groups. Following analysis of all questionnaire responses, one to one interviews were held to further explore some of the areas identified through the consultation process.

Questionnaires for people with conditions other than cancer and informal carers were distributed via the staff and support organisations with whom individuals were in contact. Opportunity was given for explanation and supportive follow up.

The following pages contain the questionnaires used in consultation.

Survey of the palliative care needs of people with conditions other than cancer

The following questionnaire was distributed in autumn 2004. 532 questionnaires were distributed and 77 were returned – a response rate of 14%.

1. If you have been told that you have one of the conditions listed below, please indicate which one you have.

Cystic fibrosis	
Heart disease/heart failure (your heart not pumping as strongly as it was before)	
HIV/AIDS	
Motor neurone disease	
Multiple sclerosis	
Muscular dystrophy	
Parkinson's disease	
Serious kidney disease	
Serious lung disease	
Other (please indicate)	

2. How much information do you have about your condition?

About as much as you would like	
More than you would like	
Not as much as you would like	

3. Where did you get this information from?

District nurse from your doctor's surgery	
Friend/family	
GP/family doctor	
Health visitor	
Hospital/clinic doctor	
Hospital nurse	
Nurse at your doctor's surgery	
Specialist nurse	
Social worker	
Support group/charity	
Other staff (please describe)	
Internet	

Library	
Magazine	
Newspaper	
Radio	
Telephone helpline	
Television	
Other (please describe)	

4. Was the information available to you locally?

Yes	
No	

5. Where would you like to be able to get information about your condition from?

Booklet/leaflet	
Internet	
Magazine	
Newspaper	
Television	
Talking to a hospital doctor	
Talking to your GP/family doctor	
Talking to a district nurse	
Talking to a health visitor	
Talking to a hospital nurse	
Talking to a social worker	
Talking to a specialist nurse for your condition	
Talking to other staff (please describe)	
Talking to other people with the same condition	
Talking to someone at a charity/support group	
Other (please describe)	

6. What information did you find most helpful?

7. Is there any other information that you would have found helpful?

If yes:

7.1 Please describe

7.2 Who do you think should have given you this information?

8. Do you ever have the opportunity to ask questions and talk with someone who knows about your condition?

8.1 If yes, who?

District nurse from your doctor's surgery	
GP/family doctor	
Health visitor	
Hospital/clinic doctor	
Hospital nurse	
Nurse at your doctor's surgery	
Specialist nurse	
Support group/charity	
Other staff (please describe)	
Other (please describe)	

8.2 If no, who would you like to be able to talk to?

District nurse from your doctor's surgery	
GP/family doctor	
Health visitor	
Hospital/clinic doctor	
Hospital nurse	
Nurse at your doctor's surgery	
Specialist nurse	
Support group/charity	
Other staff (please describe)	
Other (please describe)	

9. Do you ever get help from any of the following, or could you get it if you need it?

		Get help	Could get help
a	District nurse from your doctor's surgery		
b	Friends		
c	GP/family doctor		
d	Hospice home care team		
e	Hospital/clinic doctor		
f	Hospital nurse		
g	Husband/wife/partner		

h	Neighbours		
i	Nurse at your doctor's surgery		
j	Other people living with the same condition		
k	Priest/Minister/Chaplain		
l	Social worker		
m	Specialist nurse		
n	Support group/charity		
o	Work mates/school/college friends		
p	Other family		
q	Other staff (please describe)		
r	Other (please describe)		

10. Of the people listed in question 9, who do you get the most help from (please indicate eg a,b,c)

11. Of the people listed in question 9, who would you like to get more help from (eg a,b,c)

12. Please indicate whether you have help or would like to have help with the things listed in the table below.

	You have help	You would like help
Communicating		
Eating and drinking		
Getting around outside (by walking or by wheelchair)		
Going out on public transport		
Going to the toilet		
Household chores		
Leading the kind of social life you would like		
Moving about the house		
Preparing food/drinks		
Shopping		
Washing and dressing		
Other (please describe)		
Any additional comments		

13. Please tick the other things in the list below that you have or would like

	Have	Would like
Different people responsible for your care (eg hospital doctors and your GP) communicating well with each other		
Extra help to give families and carers time off		
Help available at evenings and weekends		
Help for your family to learn how to cope with your condition (eg lifting and moving, eating, communicating etc)		
Information and advice about how to keep your job/be able to work		
Information on benefits and financial matters		
Information on holidays and travel		
Information on how to find help		
Professionals (eg doctors, nurses, social workers) who understand about your condition		
Someone available on the telephone for advice and support for you and your family		
Someone to talk to about spiritual matters such as hopes, fears, anxieties and beliefs		
Other (please describe)		

14. Do you think that the amount of help you get is

About as much as you would like	
More than you would like	
Not as much as you would like	
Any additional comments	

15. Please tick the box(es) next to any adaptations or equipment that you have or feel you need to help you live with your condition

	Have	Feel you need	Expect to need in the near future
Adapted bathroom			
Adapted cutlery			
Adapted kitchen			
Aid to pick things up off the floor			
Bed			

Book stand			
Community alarm			
Dressing aids			
Easy chair			
Hoist			
Magnifier			
Motability car			
Page turner			
Ramp access			
Safety rails			
Shower chair			
Stair lift/other lift			
Toilet raiser			
Trolley			
Walking frame			
Wheelchair			
Widened doors			
Other (please describe)			

16. If you have physical symptoms caused by your medical condition (eg pain, breathlessness, feeling sick) what are the symptoms that have the most effect on your quality of life?

16.1 How do they impact on your life?

16.2 Do you feel that you would like to have more help with these?

Yes	
No	
Any additional comments	

17. If you had to sum up what kind of help would make the most difference to coping with your condition, what would it be?

Thank you

Thank you very much indeed for completing this questionnaire. We are very grateful for the time and effort this has taken. Your answers will help us to understand the needs of people with illnesses such as yours.

Survey of the needs of people helping to look after relatives/friends with conditions other than cancer

The following questionnaire was distributed in autumn 2004. 680 questionnaires were distributed and 111 were returned – a response rate of 16%.

Thank you for taking the time to complete this questionnaire, which you will have received if you are closely involved in the care of someone with a long-term condition. We realise that there are already many demands on your time and so we are particularly grateful for your help.

About the person you care for

1. What is your relationship to the person you care for?

Friend	
Husband/wife/partner	
Neighbour	
Son/daughter	
Parent	
Other (please describe)	

2. Is the person you care for male or female?

3. Which of these medical conditions does the person you care for have?

Cystic fibrosis	
Dementia	
Heart disease/heart failure (their heart not pumping as strongly as it was before)	
HIV/AIDS	
Motor neurone disease	
Multiple sclerosis	
Muscular dystrophy	
Parkinson’s disease	
Serious kidney disease	
Serious lung disease	
Other (please describe)	

4. For how long has he/she needed your help?

Less than 1 year	
1 – 2 years	
3 – 4 years	
More than 5 years	

5. Does he/she also receive help from anyone else?

5.1 If yes, is this

Weekdays	
Weekends	
Every other day	
2-3 times per week	
Occasionally	
Any additional comments	

6. Does the person you care for have a care package agreed by their health and social care team?

If yes:

6.1 Does the person you care for feel that the care package meets their physical needs?

6.2 Do you feel that the care package meets their physical needs?

6.3 Does the person you care for feel that the care package meets their other needs (eg social, emotional, practical)?

6.4 Do you feel that the care package provided meets their other needs (eg social, emotional, practical)?

6.5 Were you involved in discussions to agree what was necessary?

6.6 If yes, did you feel that your views were listened to?

If no:

6.7 Would you like to have been more involved?

About you

7. As a result of the time you spend caring:

7.1 Have you had to

Negotiate flexitime at work	
Reduce your working hours	
Give up work	
Reduce your social activities	
Any additional comments	

7.2 How much free/personal time do you have to carry out other activities of your choice?

Part of every day	
Part of most days	
A few hours a week	
Occasionally	
Any additional comments	

7.3 Do you feel that your own health has been affected?

If yes:

7.4 Have you discussed this with anyone?

About finding help

8. How much information do you have about the medical condition the person you care for has?

About as much as you would like	
More than you would like	
Less than you would like	
Any additional comments	

9. Where did you get this information from or where would you like to be able to get it?

	Received information from	Would like information to be available from
District nurse		
Friend/family		
GP (family doctor)		
Health visitor		
Hospital/clinic doctor		
Hospital nurse		
Nurse at your doctor's surgery		
Social worker		
Specialist nurse/care advisor		
Support group/charity		
The person you care for		
Other staff (please tell us who)		
Internet		
Library		
Magazine about the condition		
Newspaper		
Other magazine		
Radio		
Telephone helpline		
Television		
Other (please describe)		
Any additional comments		

10. What information did you find most helpful?

11. Is there any other information that you would have found helpful?

If yes

11.1 Please describe

11.2 Who do you think should have given you this information?

12. If you needed more support/help/advice, would you know where to find it?

12.1 If yes, how did you find out where to go?

13. Do you ever have the opportunity to ask questions and talk on your own to someone who knows about looking after a person with this condition?

13.1 If yes, who?

13.2 If no, would you like to be able to talk to someone?

13.3 If so, who?

14. Have you ever had any advice or training on how to look after the person you care for? (eg lifting, diet and nutrition, speech difficulties, dealing with challenging behaviours)

14.1 If yes, what was it?

14.2 If you have had advice or training, did you find it useful?

14.3 If you have not had any advice or training, do you think you would you find it useful to have some?

15. Is there anything in the list below that you have which helps you to cope OR that you think would help if you did have it? (please tick as many as you would like)

	Helps	Would help
Doctors, nurses and others involved talking to each other and sharing information and records		
Doctors, nurses and others understanding the condition and what it means for you and the person you care for		
Extra help to give you time off		
Help available at evenings and weekends		
Help for you to learn more about how to cope as a carer (eg lifting and moving, eating, communicating etc)		
Help with other areas of your life (eg housework, shopping)		
Information and advice on benefits and financial matters		
Information on holidays and travel		
Information on how to find help/advice/support		
Meeting other people in a similar situation to yourself		
Someone available on the telephone for advice and support for yourself		
Someone to talk to about spiritual matters such as your hopes, fears, anxieties and beliefs		
Anything else		
Any additional comments		

16. If the person you care for has physical symptoms as a result of their medical condition (eg pain, breathlessness, feeling sick), what are the symptoms that cause you, as a carer, the most concern?

17. If the person you care for has symptoms that concern you, what is it about them that concerns you most?

18. Do you feel that these symptoms are controlled as much as you would like?

19. Is the person you care for ever looked after by someone else to give you a break?

19.1 If yes, how frequently?

Once a week	
Once a month	
Once a year	
Occasionally	
Any additional comments	

19.2 If no, is this an opportunity that you and the person you care for would welcome?

20. If you had to sum up what would make the most difference to coping with your caring responsibilities, what would you say (you can continue on a separate sheet if you wish)?

Thank you

Thank you very much indeed for completing this questionnaire. We are very grateful for the time and effort this has taken. Your answers will help us to understand the needs of people in similar situations to yourself.

Survey of the palliative care education/training needs of generic health and social care professionals

The following questionnaire was distributed in the autumn of 2004. 1,214 questionnaires were distributed and 429 were returned – a response rate of 35%.

Definitions of general and specialist palliative care were provided on this questionnaire.

1. What is your job title?

2. Where do you see most of your patients (eg hospital/clinic, at home, care home)?

3. Please indicate if you are currently involved in the care of people with the following conditions in the course of your work

Cystic fibrosis	
Dementia	
Heart failure	
HIV/AIDS	
Motor neurone disease	
Multiple sclerosis	
Muscular dystrophy	
Parkinson's disease	
Renal failure	
Respiratory failure	
Other (please describe)	

4. Which geographical area do you work in?

5. Are you supported by a multidisciplinary team?

6. Do you consider it part of your role to provide palliative care?

7. How would you describe your understanding of palliative care?

Insufficient for your role	
Adequate for your role	
More than adequate for your role	
Any additional comments	

8. How confident are you on a day to day basis in being able to meet the general palliative care needs of any of your patients who need it?

Not at all	
Confident	
Very confident	
Any additional comments	

9. What support is available to you to meet the palliative care needs of patients in your care (eg access to specialist colleagues, advice, training etc)?

10. Do you know how to refer your patients for specialist palliative care if you or they feel they need it?

11. What procedures do you follow to do this?

12. Do you feel that specialist palliative care providers work in collaboration with you to meet the needs of patients in your care?

13. What kind of palliative care support, in addition to that which you are currently aware of, do you think would most benefit your patients?

14. If you have had education and training in palliative care in the last three years, how relevant was it to your role?

Insufficient for your role	
Adequate for your role	
More than adequate for your role	
Any additional comments	

15. Would you like the opportunity to attend education/training in palliative care?

16. If you did wish to attend education/training in palliative care, would you have access to it?

    If so, would you be given?

Funding for the education/training	
Study leave	
Travel expenses	
Any additional comments	

17. Are there any barriers that you feel stop you from attending education/training in palliative care?

18. Please indicate any areas in the list below where you feel that you would benefit from further education/training

Assessing and managing physical symptoms		
1	Anorexia and cachexia	
2	Breathlessness	
3	Constipation	
4	Communication difficulties	
5	Difficulty eating, drinking and swallowing	
6	Dyspnoea	
7	Fatigue	
8	Insomnia	
9	Lymphoedema	
10	Memory and cognitive problems	
11	Nausea and vomiting	
12	Pain	
Psychosocial and spiritual issues		
13	Anxiety	
14	Being comfortable with own spiritual issues	
15	Depression	
16	Emotional distress	
17	Financial matters	
18	Helping people to maintain their dignity	
19	Loss and bereavement	
20	Making choices available to patients	
21	Principles of palliative care	
22	Providing emotional support to carers	
23	Respecting individual differences and dignity	
24	Supporting people in expressing their hopes, fears and anxieties and the things that are important to them	
25	Understanding roles and relationships	
Team working		
26	Managing professional interfaces	
27	Understanding different care systems	
28	Understanding available resources	
29	Working within referral protocols	
	Other (please describe)	

19. Of the areas listed in question 18, which would you identify as your priorities for future learning (eg 1,2,3)

20. Is there anything else that you feel would help you to deliver palliative care? (If yes, please describe).

21. Please write any other comments you would like to make in the box below (you can continue on a separate sheet if you wish).

Thank you for taking part in this questionnaire, which forms part of a national consultation exercise to identify the palliative care training needs of health and social care professionals working in a variety of care settings. The results will be used to develop pilot educational interventions to support the needs identified and to inform a national report.

Survey: specialist palliative care for people with non-malignant conditions

The following questionnaire was distributed in the autumn of 2005 to providers of specialist palliative care. 326 questionnaires were distributed and 184 were returned – a response rate of 56%.

Thank you for taking the time to complete this questionnaire, which forms part of the national consultation exercise of the Scottish Partnership for Palliative Care Big Lottery Fund project 'Increasing access to palliative care for people with life-threatening conditions other than cancer'.

This questionnaire is being sent to people in a range of different professions involved in specialist palliative care. Please feel free to leave blank any questions which you feel are not relevant to your area.

(Please note that for the purposes of this questionnaire, 'non-malignant conditions' refers to progressive, life-threatening conditions other than cancer).

1. What is your job title?

2. Where is your job based (eg hospice, acute hospital, community)?

3. Please indicate if you are ever involved in the care of people whose primary or main illness is one of the following non-malignant conditions in the course of your work.

1	Cystic fibrosis	
2	Dementia	
3	Heart failure	
4	HIV/AIDS	
5	Huntington's disease	
6	Motor neurone disease	
7	Multiple sclerosis	
8	Muscular dystrophy	
9	Parkinson's disease	
10	Renal failure	
11	Respiratory failure	
12	Other (please specify)	

4. Which geographical area do you work in?

5. Please indicate when you tend to be involved with people who have the following conditions.

		You can tick more than one box	
	Condition	During the earlier stages of living with a condition	When people are actively dying
1	Cystic fibrosis		
2	Dementia		
3	Heart failure		
4	HIV/AIDS		
5	Huntington's disease		
6	Motor neurone disease		
7	Multiple sclerosis		
8	Muscular dystrophy		
9	Parkinson's disease		
10	Renal failure		
11	Respiratory failure		
12	Other (please specify)		

6. Are there any other non-malignant conditions not listed in question 3 where you feel that specialist palliative care would be appropriate?

7. What percentage of your patients do you estimate currently have non-malignant conditions?

8. What percentage of your time do you estimate that you spend with these patients?

9. Please indicate in the table below the care settings within which you see people with each of the conditions listed.

	Condition	Hospital	Hospice	At home	Care home	Outpatient clinic	Day facilities
1	Cystic fibrosis						
2	Dementia						
3	Heart failure						
4	HIV/AIDS						
5	Motor neurone disease						
6	Multiple sclerosis						
7	Muscular dystrophy						
8	Parkinson's disease						
9	Renal failure						
10	Respiratory failure						
11	Huntington's disease						
12	Other (please specify)						
Comments							

10. Are you in general satisfied with the level of care you are able to provide for your current patients with non-malignant conditions?

11. What is your perception of the impact of your involvement with people with non-malignant conditions on your overall workload?

12. Are there any specific referral criteria for people with non-malignant conditions in use in your area?

13. From whom do you receive referrals for people with non-malignant conditions? (please list all).

14. Do you feel in general that the people referred to you with non-malignant conditions have specialist palliative care needs?

15. Have you ever been unable to accept referral(s) for people with a non-malignant condition?

16. What do you think are the main reasons why people with non-malignant conditions who could benefit from specialist palliative care may not be currently referred?

17. Is there any additional information or support which you feel would be helpful to you in providing specialist palliative care for people with non-malignant conditions?

18. How do you think increasing access to specialist palliative care for people with non-malignant conditions could be best managed?

19. Please add any additional comments you would like to make in the box below (continue on a separate sheet if you wish).

Thank you once again for taking the time to complete this questionnaire. Your participation is very much appreciated.

Questionnaire for NHS Boards: palliative care for people with non-malignant conditions

The following questionnaire was distributed in spring 2006 to all NHS Boards in Scotland. 14 questionnaires were distributed and 12 were returned – a response rate of 86%.

Thank you taking the time to complete this questionnaire, which forms part of the national consultation exercise of the Scottish Partnership for Palliative Care Big Lottery Fund project 'Increasing access to palliative care for people with life-threatening conditions other than cancer'.

We have already consulted people with a range of life-threatening conditions other than cancer, informal carers, generic health and social care professionals and providers of specialist palliative care. We are now consulting with NHS Boards, local authorities and voluntary organisations to identify existing and planned needs assessments and palliative care strategies to meet the palliative care and information support needs of people with life-threatening conditions other than cancer.

1. Does your Board have any current palliative care strategies which specifically include the palliative care needs of people with life-threatening conditions other than cancer?

If not:

1.1 What plans are there for developing these in the future?

If so:

1.2 What are the key issues for your Board in implementing them?

1.3 Have any of these strategies been developed in partnership with local authorities?

1.4 Have any of these strategies been developed in partnership with voluntary organisations?

2. Have any detailed palliative care needs assessments for this group been carried out?

If yes:

2.1 What plans are there for this work to be done in the future?

If not:

2.2 To what extent are the findings reflected either in the current palliative care strategy of in the Board's future plans?

3. Has any scoping been carried out of the palliative care services available, via either health or social care, for this patient group?

If not:

3.1 What plans are there to do this in the future?

If yes:

3.2 What are the key issues for your Board resulting from this?

4. Our project consultation findings to date suggest that there is a need for increased collaboration between health and social care professionals in order to meet the palliative care needs of this patient group.

4.1 What do you think are the current barriers to bringing this about?

4.2 How do you think these can be overcome?

4.3 Are there any examples of good practice in this area that you would be happy for us to share with others in our final report?

5. Please add any additional comments you would like to make.

Thank you once again for taking the time to complete this questionnaire. Your participation is very much appreciated.

Questionnaire for local authorities: palliative care for people with non-malignant conditions

The following questionnaire was distributed in spring 2006 to all local authorities in Scotland. 32 questionnaires were distributed and 27 were returned – a response rate of 84%.

Thank you taking the time to complete this questionnaire, which forms part of the national consultation exercise of the Scottish Partnership for Palliative Care Big Lottery Fund project 'Increasing access to palliative care for people with life-threatening conditions other than cancer'.

We have already consulted people with a range of life-threatening conditions other than cancer, informal carers, generic health and social care professionals and providers of specialist palliative care. We are now consulting with NHS Boards, local authorities and voluntary organisations to identify existing and planned needs assessments and palliative care strategies to meet the palliative care and information support needs of people with life-threatening conditions other than cancer.

1. Does your local authority have any current strategies which specifically include people with life-threatening conditions other than cancer and would cover their palliative care needs?

If not:

1.1 What plans are there for developing these in the future?

If so:

1.2 What are the key issues for your local authority in implementing them?

1.3 Have any of these strategies been developed in partnership with NHS Boards?

1.4 Have any of these strategies been developed in partnership with voluntary organisations?

2. Have any detailed palliative care needs assessments for this patient group been carried out?

If not:

2.1 What plans are there for this work to be done in the future?

If yes:

2.2 To what extent are the findings reflected either in the current palliative care strategy or in the local authority's future plans?

3. Has any scoping been carried out of the palliative care services available for this patient group?

If not:

3.1 What plans are there to do this in the future?

If yes:

3.2 What are the key issues for your local authority resulting from this?

4. Our consultation findings to date suggest that there is a need for increased collaboration between health and social care professionals in order to meet the palliative care needs of this patient group.

4.1 What do you think are the current barriers to bringing this about?

4.2 How do you think these can be overcome?

4.3 Are there any examples of good practice in this area that you would be happy for us to share with others in our final report?

5. Please add any additional comments you would like to make.

Thank you once again for taking the time to complete this questionnaire. Your participation is very much appreciated.

Questionnaire for voluntary organisations: palliative care for people with non-malignant conditions

The following questionnaire was distributed in spring 2006 to voluntary organisations representing the conditions covered in the project. 10 questionnaires were distributed and 7 were returned – a response rate of 70%.

Thank you for taking the time to complete this questionnaire, which forms part of the national consultation exercise of the Scottish Partnership for Palliative Care Big Lottery Fund project 'Increasing access to palliative care for people with life-threatening conditions other than cancer'.

We have already consulted people with a range of life-threatening conditions other than cancer, informal carers, generic health and social care professionals and providers of specialist palliative care. We are now consulting NHS Boards, local authorities and voluntary organisations to assist us in understanding the key policy and planning issues which are involved when meeting the needs of this group of people.

The World Health Organization (WHO) defines palliative care as:

'an approach which improves quality of life of patients and their families facing life-threatening illness through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems'.

Palliative care needs

1. Does your organisation actively promote the palliative care needs of your members?

1.1 **If yes**, how to you do this?

1.2 **If not**, are there any plans to do so?

2. What are the key palliative care issues for your members?

3. What are the key issues for your organisation in promoting wider recognition of the palliative care needs of your members?

Palliative care needs assessments

4. Have you ever been asked to participate in the development of palliative care needs assessments which include people with **name of condition here** with:

4.1 NHS Boards?

4.2 Local authorities?

5. Have you ever actively participated in the development of palliative care needs assessments which include people with **name of condition here** with:

5.1 NHS Boards?

5.2 Local authorities?

If not:

5.3 What plans are there for this work to be done in the future?

If so:

5.4 What are the key issues for your organisation identified through needs assessments?

Palliative care services

6. Have you been involved in any scoping of the palliative care services available to people with **name of condition here**?

If not:

6.1 What plans are there to do this in the future?

If so:

6.2 What are the key issues for your organisation and the people whom you support highlighted through the scoping of services?

6.3 Please give details of which organisations were involved

Palliative care strategies

7. Have you ever been consulted on the development of palliative care strategies for people with **name of condition here** by:

7.1 NHS Boards?

7.2 Local authorities?

8 Have you actively participated in the development of palliative care strategies which include people with **name of condition here** with

8.1 NHS Boards?

8.2 Local authorities?

If not:

8.3 What plans does your organisation have to try to influence the future development of palliative care strategies for people with **name of condition here** by NHS Boards and/or local authorities?

If so:

8.4 What are the key issues for your organisation and the people you support in implementing such strategies?

9. Our project consultation findings to date suggest that there is a need for increased co-ordination of health and social services in order to meet the palliative care needs of this patient group.

9.1 What do you think are the current barriers to bringing this about?

9.2 How do you think these can be overcome?

10. Are there any examples of good practice in meeting the palliative care needs of your members that you would be happy for us to share with others in our final report?

Thank you once again for taking the time to complete this questionnaire. Your participation is very much appreciated.

Appendix 2

Palliative care study day

Appendix 2: palliative care study day

The educational needs of generic health and social care professionals identified through our consultation exercise were used to develop a study day, which has been successfully piloted with 136 participants in six different venues throughout Scotland. The study day content has been developed for use beyond the life of the project. The following pages contain the programme, individual study day sessions and information on the teaching methodology used. The study day programme and sessions can also be downloaded as a single item from the Partnership's website on www.palliativecarescotland.org.uk.

Study day programme

Does this patient need palliative care?
Recognising the need for palliative care for people with non-malignant conditions

09.00 – 09.15 **Registration**

09.15 – 10.00 **What do we mean by palliative care?**

- a holistic approach to care
- principles of general palliative care
- the role of specialist palliative care

Meeting the palliative care needs of people with non-malignant conditions

- what are the palliative care needs of people with non-malignant conditions?
- how can they best be met?
- by whom?

10.00 – 10.15 **Coffee**

10.15 – 12.30 **Assessing and responding to some difficult symptoms**

How to recognise when someone is in pain

- defining and recognising pain
- accessing help, support and advice

Causes of fatigue and its effects on quality of life

- what might this mean for people with non-malignant conditions and their carers?
- how to access help, support and advice

Dealing with anxiety and emotional distress

- identifying and responding to distress
- answering difficult questions
- helping people express their feelings and anxieties and being able to deal with this
- identifying and meeting information needs of patients and carers from diagnosis onwards
- identifying and accessing appropriate support (for patients, families and professionals)

12.30 – 13.15 Lunch

13.15 – 14.15 Assessing and responding to key issues towards the end of life

- recognising patient and family transition to this phase
- supporting the acknowledgment that things have changed
- identifying relevant issues (physical, social, emotional)
- identifying and agreeing appropriate care settings
- addressing concerns and expectations
- accessing help, support and advice (for patients, families and professionals)

14.15 – 14.30 Tea

14.30 – 16.00 Understanding the patient's journey

Interactive case studies will be used to further explore issues arising at key stages of the patient's journey

- at the time of diagnosis
- whilst the person is living with the condition as it progresses
- towards the end of life

16.00 – 16.30 Evaluation and close

Study day session 1 – what do we mean by palliative care?

Study day session 1 (1 hour)

Aim

- to develop an understanding of the potential need for palliative care for people with a non-malignant condition

Learning outcomes

At the end of the session, participants will be able to:

- discuss the meaning and scope of palliative care
- describe the philosophy and principles of palliative care within a multi-professional context
- analyse how the palliative care approach can be applied to people with a non-malignant illness
- discuss how palliative care needs can be met and by whom.

Overview

This session aims to enable participants to develop an understanding of the palliative care needs of people with non-malignant conditions and sets the overall scene for the unfolding content of the study day. The focus is on the general nature of palliative care, its philosophy and principles and how these may be applied to the care of people with non-malignant conditions. Contemporary statements are referred to when considering the palliative care needs of this group. The spectrum of palliative care, definitions and applications are discussed eg the palliative care approach, general palliative care and specialist palliative care. The responsibilities of all health and social care professionals and the first order ethical principles are explained using the palliative care approach as a template of care for people with life-threatening conditions other than cancer, and attention is drawn to the influence of changing epidemiology and health needs.

Participants are asked to reflect on their own practice experience and to think about the key issues of care for the person with a life-threatening condition other than cancer, their family and the health and social care professionals involved in their care. A brief overview of how these needs might be met is given. The role of specialist palliative care is outlined and possible levels of intervention discussed in terms of supporting generic health and social care professionals in the care of people with advancing non-malignant illness.

Key content

- philosophy and principles of palliative care
- defining the scope of palliative care
- palliative care approach
- palliative interventions
- general palliative care
- specialist palliative care
- changes in epidemiology and health needs
- diagnosing the need
- key issues for care
- ethical considerations

Teaching approach

Because it is known that overall knowledge about palliative care is weak, this session is delivered using a modified or structured lecture. Reflective issues are elicited from the participants by continual relation to practice.

Supporting literature

Connolly, M (2000) *Patients with non-malignant disease deserve an equitable service.* International Journal of Palliative Nursing. Vol 6 (2).

Fallon, M and Neill, B (1998) *ABC of palliative care.* BMJ Books.

The National Council for Palliative Care (2005). *The shape of the future for palliative care.* 20:20 Vision.

Trau, D and Ross, J (2005) *Palliative care in non-malignant disease.* Journal of the Royal Society of Medicine. Vol. 98.

Study day session 2 – how to recognise when someone is in pain

Study day session 2 (½ hour)

Aims

- to explore the concept of total pain
- to explore the role of the multidisciplinary team in the management of pain

Learning outcomes

At the end of the session, participants will be able to:

- define pain and total pain
- describe how pain can be assessed
- identify and discuss good practice in the management of pain
- reflect upon practice and discuss other influencing factors in the management of pain.

Overview

The aim of this session is to introduce participants to the concept of total pain and to explore the role of the multidisciplinary team members in assessment. Some approaches to management are also explored.

The key issue in this session is to provide a basic foundation of knowledge to an audience of mixed experience and to facilitate their appreciation of the skills they have in their own professional role.

For this session a modified lecture is used with some discussion and reflection on current practice. This enables the identification of experience and possible future training needs. To provide this level of information, some definitions of pain are given. The concept of total pain is explored in relation to pain assessment and some examples of common assessment tools are discussed. The World Health Organization (WHO) analgesic ladder is described along with other aspects of good practice in pain management eg accurate assessment and the multi-professionals approach with effective communication between team members. A brief mention is made of the importance of the fact that consideration of psychosocial aspects can affect the level of pain experienced.

Key content

- definitions of pain
- pain assessment, including examples of pain assessment tools
- approaches to pain management, including use of the WHO analgesic ladder
- complementary approaches
- psychosocial influences on pain
- evidence of best practice
- how to access help and advice

Teaching approach

- learning outcomes will be achieved by a modified lecture and interactive discussion using reflection on delegates' individual practice issues and roles.

Supporting literature

Davies, J and McVicar, A (2000). *Issues in effective pain control 2: From assessment to management.* International Journal of Palliative Care Nursing. 6 (4) 162-168.

Scottish Intercollegiate Guidelines Network (2000). *Control of pain in patients with cancer: a national clinical guideline.* SIGN Publication number 44. (www.sign.ac.uk).

Twycross, R (1999) *Introducing palliative care*. Radcliffe Medical Press 3rd Ed. Part 3 p61-95.

Study day session 3 – causes of fatigue and its effects on quality of life

Study day session 3 (½ hour)

Aim

- to understand the effects of fatigue on people with an advanced illness

Learning outcomes

At the end of the session, participants will be able to:

- understand the concept of fatigue
- examine the causes and assessment of fatigue
- discuss the possible reversible causes of fatigue
- explore and discuss the meaning of fatigue for the patient and the family
- consider some approaches to fatigue management.

Overview

The aim of this session is for participants to appreciate and understand the causes and effects of fatigue on a person with advancing illness.

The key focus in this session is to highlight the relatively poorly understood phenomenon of fatigue and its prevalence and impact on function and quality of life.

The presentation follows a modified lecture approach which encourages participants to think about their own practice experiences and to develop a multi-professional perspective on management.

The session identifies the multidimensional concept of fatigue, its definition and subjective experience and its comparison to other distressing symptoms experienced by people with advancing illness.

Key approaches to assessment and some measurement tools are outlined. The importance of assessing for possible reversible causes eg anaemia, depression, infection etc are explained and the importance of individualised approaches and regular monitoring are discussed. Some suggestions are given as to the management of fatigue.

Key content

- definitions of fatigue
- assessment of fatigue, including examples of assessment tools
- potential reversible causes
- impact of fatigue on quality of life
- approaches to management
- support for the patient and family

Teaching approach

- learning outcomes will be achieved by a modified lecture and interactive discussion using reflection on delegates individual practice issues and roles

Supporting literature

Loge, J (2003) *Unpacking fatigue*. European Journal of Palliative Care. 10 (2) Supplement.

Ream, E and Richardson, A (1999) *From theory to practice: designing interventions to reduce fatigue in patients with cancer*. Oncology nursing forum 26 (8): 1295-1303.

Study session 4 – dealing with anxiety and emotional distress

Study day session 4 (1-1½ hours)

Aim

- to explore aspects of the role of the multidisciplinary team in identifying and responding to emotional distress within families dealing with a life-threatening illness

Learning outcomes

At the end of the session, participants will be able to:

- examine and discuss the importance of good communication skills in the care of individuals and their families
- discuss and acknowledge the situations that can affect the connection between people with life-threatening conditions and their families
- explore the continuing information needs of patients and their informal carers through their disease trajectory
- gain insight into some of the difficulties in identifying and accessing appropriate support for patients, families and health and social care professionals.

Overview

The aim of this session is to explore aspects of the supporting role of each member of the multidisciplinary team in identifying and responding to disclosure of emotional distress within families dealing with a life-threatening illness. After a brief introduction to the basic theory of communication skills and reflection on what makes communication difficult, the session is developed by use of sculpting to reveal the following important issues:

- answering difficult questions
- helping people to express their feelings
- identifying and accessing appropriate support for patients, families and professionals
- identifying and meeting information needs
- identifying and responding to distress.

Key content

- basic communication skills
- barriers to communication
- exploring significant relationships for patients
- facilitating disclosure of emotions
- addressing key issues in anxiety and emotional distress
- identifying key professional roles throughout the patient's journey

Teaching approach

The teaching methodology for this session is sculpting, which is a form of dynamic non-verbal role play in which the scene is set from a given scenario representing a clinical situation in which participants arrange themselves in positions that symbolise feelings, conflicts and power relationships. This technique can be used to improve communication skills, explore family relationships and enhance team working.

Management of the sculpting session

Ideally the technique involves a group of participants and two facilitators. The number of participants will be dependent on what learning is anticipated from the case scenario. One facilitator takes a lead in conducting the exercise, the other has the work of detecting any signs of distress amongst the participants and to intervene if necessary. The method and purpose needs to be carefully explained to participants as it is a powerful way of exploring feelings and emotions that may not be expressed in a verbal communications exercise.

The tools used for this session are:

- the case scenario, outlining a clinical and social situation
- a list of roles with a brief biographical account of each.

The session takes the following format:

- a facilitator reads the case scenario
- roles are assigned to participants
- the key focus is identified – ie the person with the condition
- information cards depicting their role are given to participants
- participants read the information but do not disclose it to other participants
- the person taking the role of the person with the condition is asked to place themselves in the centre of the room
- participants are then asked to place themselves where they would perceive they should be in relation to supporting the person with the condition

- the participant playing the person with the condition is then asked if they would like to move any of the other participants (in relation to their role in the scenario)
- each participant is asked how they feel about their position
- participants are asked if they think individuals are where they would have imagined they would be or if they are surprised by the positions adopted
- the facilitator asks each person to divulge more about their role from their information cards
- the group participates in further reflection and dynamic repositioning
- the group participates in verbal feedback and group conclusion
- at the end of the sculpting session and before the evaluation the facilitator asks the participants to leave their roles and return to their seats
- evaluation (eg a discussion which identifies learning points and can be summarised on a flip chart by the facilitator).

Sculpting Scenario

Lucy is a 17 year old who was diagnosed with cystic fibrosis at the age of four months after a failure to thrive. After years of severe chest infections and now a deteriorating pulmonary function, she has been referred for consideration for a place on the lung transplant list.

Lucy lives with her parents Alan and Mary. Both have been well until Mary was diagnosed with multiple sclerosis last year which has affected her energy and mobility levels. There are two siblings, Lisa aged 20 and Mark aged 11.

Family life has frequently been disrupted by Lucy's admissions to hospital and home therapies, and although she is keen to lead as normal a life as possible, the strain of the illness and the responsibility on her parents and siblings is beginning to become an issue.

Many health and social care professionals may gradually become involved due to the evolving issues of caring for this family.

Sculpting session roles

Lucy

You are 17 years old and were diagnosed with cystic fibrosis when you were four months old. You have recently been placed on the lung transplant list. Your Mum has been your main carer and has overseen your daily activities, monitored your diet and dealt with your physiotherapy needs. She and Claire (your best friend) were your main confidants until Ross, your boyfriend, came on the scene. You are very distressed about your Mum's recent diagnosis. You are close to your Dad but feel he has a closer relationship with your siblings. You and Lisa argue a lot and you think it is because you receive more attention from your Mum than she does.

Mary (mum)

You are married to Alan and have three children. You were devastated when Lucy was diagnosed as you were unaware you carried the cystic fibrosis gene. You already had one healthy child who is a carrier of this gene, and this has not been discussed openly in your family. You were diagnosed with multiple sclerosis eight months ago and although you frequently feel tired you are coping. Your anxieties lie with who will help with Lucy's physiotherapy and other health needs. Alan has always maintained he is no help and Lisa barely talks to Lucy without arguing.

Alan (dad)

You are an only child. Both your parents have died – your mother from pancreatic cancer when you were 18 years old and your father more recently in a car accident. You are a carrier of the cystic fibrosis gene. You found this out only after Lucy's diagnosis. You are currently in turmoil. Your youngest daughter Lucy is on the lung transplant list to treat her cystic fibrosis and your wife has been diagnosed with multiple sclerosis. There is friction between Lucy and her sister Lisa and you are feeling overwhelmed and torn as to who in your family needs you more. To escape you tend to spend most weekends with your rugby friends.

Lisa (older sister)

You are finding the family situation difficult. You have recently come home after your second year at university and are planning to delay returning for your third year. Your Mum has been diagnosed with multiple sclerosis and your sister Lucy is on the lung transplant list. Your relationship with both your Mum and Lucy is strained. You find Lucy irritating and feel she always gets her own way just because she has cystic fibrosis. As the eldest so much more is expected of you and you are healthy. You have great concerns about having children in the future. You are aware your aunt Anne has made a decision not to have children but feel unable to talk to your parents about this. You feel they have enough worries but feel angry that they haven't taken time to talk about the reality of your situation. This is in fact why you react to Lucy in the way you do – it is more fear that you could be responsible for having a child with cystic fibrosis than any perceived jealousy. You have a strong bond with your brother Mark.

Mark (younger brother)

You are a keen footballer and your grandfather (Mary's Dad) shares your interest. Your Dad prefers rugby so doesn't share your passion. You spend at least two evenings each week training. Your grandfather is your taxi and companion and weekends are spent playing/attending football matches with him. You are sad about your sister's and Mum's situation but try not to think about it. Lisa is your main support at home, and takes you to football if your grandfather is unable to.

Gran (Mary's mum)

You come from a reserved family. You try to support Mary but often find that she snaps at you for no reason and blames you for Lucy's cystic fibrosis. You were unaware that you carried the cystic fibrosis gene until Lucy's diagnosis. Mary is convinced you did know as there were very few children on her side of the family.

Grandfather (Mary's dad)

This is a very difficult situation which you are struggling with. Your daughter and your granddaughter are both ill. You feel guilty and wish it was you that were ill and not them. You were devastated to find that you too were a carrier of the cystic fibrosis gene after Lucy's diagnosis. You try to be there for everyone in the family but your main concern is Mark – you have a close bond with all your grandchildren but especially with Mark.

Anne (Mary's sister)

You are Mary's younger sister; there is a 12 year age gap. You feel particularly close to Mary's children. When Lucy was diagnosed you made the decision to confirm whether you were a carrier of the cystic fibrosis gene. You consciously decided not to have children when it was confirmed that you are a carrier.

General practitioner

You work in a busy medical centre. You are supportive when the family attend with problems. If they have any concerns relating to cystic fibrosis or multiple sclerosis you refer them to the local hospital team.

Community physiotherapist

You are unaware of this family.

Clinical nurse specialist for cystic fibrosis

You are hospital based and have met Lucy and some members of her family on several occasions. With the potential of a lung transplant for Lucy, you are working more closely with the transplant coordinator and hope to set up a family meeting.

Transplant coordinator

You are based with the hospital transplant team and have had one meeting with Lucy and her parents.

Social worker

You are unaware of this family.

Occupational therapist

You are unaware of this family.

Hospital neurological consultant

You met Mary eight months ago when she was diagnosed with multiple sclerosis. She is currently reviewed on a six monthly basis. You have referred her to the multiple sclerosis clinical nurse specialist who has made telephone contact.

Hospital Respiratory Consultant

You have known this family for 17 years and have a very good relationship with them all. You are very supportive and have made yourself readily available.

Claire – best friend

You have been friends with Lucy since primary one and have never argued! You are aware of her illness and have been quite involved with the changing pattern of her illness. You share a lot together.

Ross – boyfriend

You have been Lucy's boyfriend for six months and in that time your relationship has deepened. You have had a physical relationship and are now concerned about her frailty. Although you do not fully understand her illness you try to support her as best you can but feel frightened yourself.

School guidance teacher

You are aware of the situation and monitor Lucy when she is at school.

Psychologist

Lucy has only recently been referred to you because of her pending lung transplant.

Multiple sclerosis clinical nurse specialist

You have made telephone contact with Mary but she has declined a visit at this stage. Contact numbers have been left.

Dietician

The only contact you have had with Lucy and her family is during in-patient admissions.

Health Visitor

You are based in the GP practice building and aware of the family, but have no regular contact.

Supporting literature

Dunne, K (2005) *Effective communication in palliative care*. Nursing standard. 20.13, 57 – 64.

Jeffrey, D (2002) *Teaching in palliative care: a practical guide*. Radcliffe Medical Press.

Lloyd-Williams, M (2003) *Psychosocial issues in palliative care*. Oxford University Press.

Wallace, P (2001) *Improving palliative care through effective communication*. International Journal of Palliative Nursing 7 (2): 86-90.

Study day session 5 – assessing and responding to key issues towards the end of life

Study session 5 (1¼ hours)

Aims

- to develop an understanding of the psychological, physical, social, spiritual and ethical implications for patients and their families towards the end of life
- to critically examine the role of the multi-professional team in recognising and preparing for this stage

Learning outcomes

At the end of the session, participants will be able to:

- recognise and support the transition to end of life care
- identify the relevant issues for patients and families
- consider the appropriate management of end of life care
- discuss appropriate health and social care professional input and care settings.

Overview

At the pilot study days, this session was delivered by a local consultant in palliative medicine. The intention of the session is to enable participants to:

- develop an appreciation of the complex disease trajectories experienced by people with life-threatening conditions other than cancer
- recognise the signs and symptoms of impending death.

The session highlights the importance of communication with the dying person and their family as well as some of the ethical issues around delivering appropriate treatment and care. Key points discussed in this session are:

- the goals for the last days of life
- the role of the multidisciplinary team
- the role of specialist palliative care services
- the importance of considering and supporting the individual needs of the patient and their families eg their values, needs and preferences.

Issues around difficult conversations and responding to the preferred place of care are examined in the context of choices and resources. Participants are introduced to the value of awareness of and access to standards and clinical guidelines for use across all care settings to disseminate best practice palliative care.

The Liverpool Integrated Care Pathway for the Dying Patient, which highlights the need to deliver holistic care during the dying phase and gives guidance on the different aspects of care required, is used to illustrate optimum end of life care.

Key content

- understanding disease trajectories in non-malignant conditions
- triggers for palliative care
- estimating prognosis
- recognising when someone is dying – clinical indicators
- responses to a terminal diagnosis
- ethical issues around delivering treatment/care
- assessment of patients/relatives needs
- goals for the last days of life, including the Liverpool Care Pathway for the Dying Patient
- place of care
- the role of the multidisciplinary team
- the role of specialist palliative care

Teaching approach

- learning outcomes are achieved through a modified lecture, reflective discussion and questions on practical issues

Supporting literature

Ellershaw, J and Wilkinson, S (2003) *Care of the dying: a pathway to excellence*. Oxford University Press.

Fallowfield, LJ, Jenkins, VA and Beveridge, HA (2002) *Truth may hurt but deceit hurts more: communication in palliative care*. Palliative Medicine. 16: 297 – 303.

Study day session 6 – understanding the patient's journey

Study session 6 (1 hour)

Aim

- to develop an understanding of the different issues arising throughout the different stages of a life-threatening illness

Learning outcomes

At the end of the session, participants will be able to:

- consider and reflect upon the key issues of the impact of a life-threatening illness on the person and their family
- critically consider the issues that may be important for a person with a life-threatening condition and their family at different stages of an illness
- explore the professional roles and health and social care services that may be relevant at different stages of the patient's journey.

Overview

The aim of this session is for participants to develop an understanding of the different issues and needs which may arise throughout the different stages of a life-threatening illness.

A problem-based learning approach is used, with three fictional case studies depicting different stages of the illness trajectory. These are:

- diagnosis
- living with a non-malignant condition
- dying from a non-malignant condition.

Case studies usually involve making decisions about particular courses of action and to some extent capture the reality of actual situations. For this session the participants are placed in three groups with an equal representation from the attending professional groups wherever possible. A brief scenario is outlined and the participants in each group are asked to consider some questions which are relevant to the particular stage of the patient's journey. Each group then feeds back to the whole group.

Key content

- the illness trajectory – diagnosis, the journey (living with a life-threatening condition and dying from a life-threatening condition)
- key issues for each stage
- proactive management

- person-centred care
- the palliative approach
- general palliative care
- specialist palliative care
- supporting the patient and their family
- communication

Case studies

Case Study 1: diagnosis

Paul is a 45 year old man who initially complained of weakness in his legs. This was first attributed to stress as it coincided with establishing his own car hire business.

He has recently been diagnosed with progressive supranuclear palsy (PSP). He is married with three teenage children, his wife Carol has a part-time job and at other times helps him with the administration of his business.

The group is given the following questions to consider:

- what are some of the potential consequences of the diagnosis?
- what are the likely questions to be asked following the diagnosis?
- what are the important issues of management at this stage?
- what professional health and social care services might be beneficial for Paul and his family?

Case study 2: living with a non-malignant condition

Janet is a 40 year old woman with severe respiratory disease. She lives alone and has recently had several emergency admissions to hospital due to breathlessness. Her frailty has increased. Janet is a very independent lady and has few social contacts other than a sister and friends from a reading group who meet up regularly in a local club.

The group is given the following questions to consider:

- what potential problems may need to be addressed at this stage?
- what are the implications for clinical management and proactive care?
- what professional health and social care services might be necessary and why?

Case study 3: dying from a non-malignant condition

Lily is an 82 year old lady with multiple medical problems and mild dementia. Her condition is deteriorating and her family want to have all her medication stopped and to let nature take its course. Lily is a retired headmistress and has always been very clear about and involved with her medical care. She has been living in a private nursing home for the past 18 months and for the last few weeks has been unable to leave her room.

The group are asked to consider the following questions:

- what discussions or plans could have been addressed prior to her deterioration?
- what important issues around the care of Lily need to be considered at this stage?
- how might you support and communicate with Lily's family?
- what professional and specialist services could be involved at this stage?

Supporting literature

Addington-Hall, JM (1998) *Reaching out: specialist palliative care for adults with non-malignant disease*. Occasional paper 14. London: National Council for Hospices and Specialist Palliative Care Services.

Murtgage, FP and Higginson, I (2004). *Patterns of dying: palliative care for non-malignant disease*. Clinical Medicine Vol 4 (1) January/February.

Additional palliative care education and training

Further information on palliative care education and training can be found at:

www.ayrshirehospice.org.uk

www.dundee.ac.uk

www.gcal.ac.uk

www.gla.ac.uk

www.mariecurie.org.uk

www.napier.ac.uk

www.palliativecarescotland.org.uk

www.paisley.ac.uk

www.standrews-hospice.com

www.stcolumbashospice.org.uk

www.stir.ac.uk

www.strathcarronhospice.org.uk

Appendix 3

Information support checklist

Appendix 3:
information support checklist

This information support checklist is intended for use within NHS Board, Community Health Partnership or local authority areas to identify sources of information and to ensure that people living with life-threatening conditions other than cancer and informal carers within their area receive the information support they need. The checklist can also be downloaded as a single item from the Partnership's website on www.palliativecarescotland.org.uk

Benefits and financial matters

Information required	**Information source**
What financial help are people with conditions other than cancer entitled to?	
When is it appropriate to apply for benefits?	
How can benefits be accessed?	
How can independent living funds be accessed?	

Condition-specific information

Information required	**Information source**
Information about specific conditions and their course	
The likely future needs (eg increasing needs for care, equipment and adaptations)	
How to access condition-specific organisations	
How to live with a non-malignant life-threatening condition and manage the symptoms of that condition	
How to access help if symptoms worsen	

Holidays and travel

Information required	Information source
How to obtain travel passes and disabled parking badges	
How to find accessible public transport, including dial-a-ride services	
How to find holiday destinations with accessible facilities	
How to access suitable travel insurance	
How to access equipment needed for holidays and travel	
How to access help whilst away from home	

How to get help to give informal carers time off

Information required	Information source
How to access facilities available in their local area (eg day centres, respite care and buddy schemes)	
How to arrange a carer's assessment	
How to make other people aware of their caring role (eg informal carers telling their GP and their employer)	
How to access local support groups	

Appendix 4

Glossary of terms

Appendix 4: glossary of terms

Assessment

The process of identifying and measuring someone's needs, or of collecting and reviewing information in order to make a decision or judgment about something.

Complex needs

Needs that cannot be addressed through simple or routine methods of care.

Community Health Partnership (CHP)

Community Health Partnerships are being established by NHS Boards as key building blocks in the modernisation of the NHS and joint services, with a vital role in partnership, integration and service redesign. CHPs will provide a focus for integration between primary care and specialist services and between health and social care.

Condition-specific

Relating to or working with a specific medical condition.

General palliative care

Palliative care provided by a person's usual carers and primary care team when they do not have complex palliative care needs. (See Palliative care, Complex needs).

End of life care

End of life care is part of palliative care, and is the care that is provided in the last stages of a person's life, often during advanced progressive illness. End of life care involves an active, compassionate approach that treats, comforts and supports the dying person. It is sensitive to personal, cultural and spiritual values, beliefs and practices and provides support for families and friends up to and including the period of bereavement. It includes terminal care. (See Terminal care).

Generic health and social care professionals

For the purposes of this report, health and social care professionals working in any field other than specialist palliative care.

GP

General Practitioner. Used to be known as family doctor. Everyone needs to be registered with a GP to access general medical care. (See also Primary health care team).

Hospice

A place where specially trained, doctors, nurses and others are committed to the care of patients with active, progressive far-advanced illness, and to the support of people who are close to them. Hospices provide specialist palliative care. (See Specialist palliative care).

Informal Carer

Someone who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care provided by such individuals is unpaid.

Integrated care pathway

A framework used by healthcare staff for planning and documenting specific aspects of care. Use of established integrated care pathways helps to ensure consistent standards of care in all care settings.

Key worker

The health or social care professional who is the first point of contact for a person with health and/or social care needs and who is responsible for co-ordinating the care required by that person and ensuring that their needs are met.

Medication

A substance administered for treatment purposes.

Multidisciplinary

A group of professionals from different disciplines who work together to provide or to improve care for people with particular needs. The members of such a team will vary according to circumstances, but will normally include both healthcare and non-healthcare representatives.

Out-of-hours care

The arrangements that are made for accessing care outwith what are regarded as normal working hours, ie between 9am and 5pm on weekdays and throughout weekends and public holidays. From 1 January 2005 GPs are not obliged to provide out-of-hours care, which is now the responsibility of NHS Boards. Calls from members of the public during 'out-of-hours' are referred through NHS24, an organisation set up as part of the NHS to deal with such telephone queries.

Palliative care

The care provided for an individual and those close to them when the individual's disease is no longer responsive to curative treatment. Palliative care is proactive, total care that aims to control physical symptoms and address social, emotional and spiritual needs. (See General palliative care, Palliative care approach and Specialist palliative care).

Palliative care approach

A person-centred and holistic approach to care which is based on palliative care principles. (See General palliative care, Palliative care and Specialist palliative care).

Primary care

Healthcare delivered outside hospitals by a primary healthcare team.

Primary healthcare team

Team composed of GPs, district and community nurses, pharmacists and others providing a range of family health services.

Prognosis

An assessment of the expected future course and outcome of a person's disease.

Progressive illnesses

Conditions which result in progressive deterioration and loss of function.

Quality of life

Term used to describe the overall assessment of a person's situation and their sense of personal well-being.

Social work services

Social work services provide advice, support and practical help for problems resulting from social circumstances. Social work services employ staff with a range of skills and qualifications, including social workers (see below) and occupational therapists.

Social worker

A social worker is a person who has obtained a specialist qualification in social work. A social worker supports vulnerable people and their carers with the aim of enhancing the quality of all aspects of their daily lives.

Specialist

A person who after education, training and experience has become an expert in their field.

Specialist palliative care

The active total care of patients with progressive, far-advanced disease and limited prognosis, and their families, by a multi-professional team who have undergone recognised specialist palliative care training and have a wide mix of skills. Specialist palliative care provides physical psychological, social and spiritual support for those with complex palliative care needs.

Specialist palliative care services

A range of services provided by specialist palliative care teams.

Support services

Services which exist to support those providing care and help them to provide the best care possible. A wide range of support services exists in the community including dieticians, chiropodists, occupational therapists, equipment providers, charity organisations etc.

Symptom

A reported feeling or observable physical sign of a person's condition that indicates some abnormality.

Terminal care

Terminal care is part of end of life care. It is specialised care during the final stages of an illness, with the emphasis on relief of symptoms in order to allow the person to feel as comfortable as possible.

World Health Organization (WHO)

A United Nations agency dealing with issues concerning health and disease around the globe.

Appendix 5

Additional reading and resources

Appendix 5: additional reading and resources

Additional reading

Addington-Hall J, and Higginson, I (Eds) (2001) *Palliative Care for Non-Cancer Patients*. Oxford University Press.

Alzheimer Scotland – Action on Dementia (2006) *Lighting up lives: A report on the palliative care needs of people with end stage dementia living in Dumfries and Galloway 2004-2006*. Alzheimer Scotland, 1 Gordon Street, Dumfries DG1 1EG; tel 01387 261303; fax 01387 251899; website: www.alzscot.org

Davies, E and Higginson, IJ (2004) *Better palliative care for older people*. World Health Organization.

Davies, E and Higginson, IJ (2004) *The solid facts*. Europe, World Health Organization.

Department of Health (DoH) (2000) *National Service Framework for Coronary Heart Disease*. Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS; tel 020 7210 4850; website: www.dh.gov.uk

Department of Health (DoH) (2001) *National Service Framework for Older People*. Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS; tel 020 7210 4850; website: www.dh.gov.uk

Department of Health (DoH) (2004) *National Service Framework for Children*. Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS; tel 020 7210 4850; website: www.dh.gov.uk

Department of Health (DoH) (2004) *Renal National Service Framework part 1 – dialysis and transplantation*. Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS; tel 020 7210 4850; website: www.dh.gov.uk

Department of Health (DoH) (2005) *Renal National Service Framework part 2 – chronic renal failure and end of life care*. Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS; tel 020 7210 4850; website: www.dh.gov.uk

Department of Health (DoH) (2005) *National Service Framework for Long Term Conditions*. Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS; tel 020 7210 4850; website: www.dh.gov.uk

Ellershaw, J and Wilkinson, S (2003) *Care of the Dying: A Pathway to Excellence*. Oxford, Oxford University Press.

Leigh, PN et al (2003) *The management of motor neurone disease*. Journal of Neurology, Neurosurgery and Psychiatry; 74: supplement iv47.

Multiple Sclerosis Society (2006) *Multiple sclerosis essentials. Support for people living with multiple sclerosis.* Multiple Sclerosis Society.

Multiple Sclerosis Society (2006) *Multiple sclerosis and palliative care. A guide for health and social care professionals.* Multiple Sclerosis Society.

National Institute for Clinical Excellence (2003) *Management of chronic heart failure in adults in primary and secondary care.*

National Institute for Clinical Excellence (2003) *Management of multiple sclerosis in primary and secondary care.*

National Institute for Clinical Excellence (2006) *Diagnosis, management and treatment of adults with Parkinson's disease in primary and secondary care.*

National Institute for Clinical Excellence (due 2006) *The treatment and care of people with dementia in health and social care.*

Nodder, D et al (2000) *Multiple sclerosis: care needs for 2000 and beyond.* Journal of the Royal Society of Medicine 2000; 93 (5): 219-224.

Oliver, D and Webb, S (2000) *The involvement of specialist palliative care in the care of people with motor neurone disease.* Palliative Medicine 14, 427-8.

Scottish Executive Health Department (2000) *Our National Health – a plan for action, a plan for change.* St Andrews House, Regent Road, Edinburgh EH1 3DG; tel 0131 556 8400; fax 01397 795001; website: www.scotland.gov.uk/about/departments

Scottish Executive Health Department (2000) *Coronary Heart Disease and Stroke Strategy for Scotland.* St Andrews House, Regent Road, Edinburgh EH1 3DG; tel 0131 556 8400; fax 01397 795001; website: www.scotland.gov.uk/about/departments

Scottish Executive Health Department (2001) *Cancer in Scotland: Action for change.* St Andrews House, Regent Road, Edinburgh EH1 3DG; tel 0131 556 8400; fax 01397 795001; website: www.scotland.gov.uk/about/departments

Scottish Executive Health Department (2005) *Delivering for Health.* St Andrews House, Regent Road, Edinburgh EH1 3DG; tel 0131 556 8400; fax 01397 795001; website: www.scotland.gov.uk/about/departments

Scottish Executive Health Department (2005) *Building a health service fit for the future.* St Andrews House, Regent Road, Edinburgh EH1 3DG; tel 0131 556 8400; fax 01397 795001; website: www.scotland.gov.uk/about/departments

Scottish Executive Health Department (2006) *The Future Care of Older People in Scotland.* St Andrews House, Regent Road, Edinburgh EH1 3DG; tel 0131 556 8400; fax 01397 795001; website: www.scotland.gov.uk

Scottish Executive Health Department (2006) *The Future of Unpaid Care in Scotland.* St Andrews House, Regent Road, Edinburgh EH1 3DG; tel 0131 556 8400; fax 01397 795001; website: www.scotland.gov.uk

Scottish Partnership for Palliative Care (2001) *Palliative Care for all. Responding to need not diagnosis*. 1a Cambridge Street, Edinburgh EH1 2DY; tel 0131 229 0538; fax 0131 228 2967; website: www.palliativecarescotland.org.uk

Scottish Partnership for Palliative Care (2001) *Palliative Care for Young People aged 13-24*. 1a Cambridge Street, Edinburgh EH1 2DY; tel 0131 229 0538; fax 0131 228 2967; website: www.palliativecarescotland.org.uk

Scottish Partnership for Palliative Care (2003) *Palliative Care in Community Hospitals in Scotland. A framework for good practice*. 1a Cambridge Street, Edinburgh EH1 2DY; tel 0131 229 0538; fax 0131 228 2967; website: www.palliativecarescotland.org.uk

Scottish Partnership for Palliative Care (2006) *Public Awareness of Palliative Care*. 1a Cambridge Street, Edinburgh EH1 2DY; tel 0131 229 0538; fax 0131 228 2967; website: www.palliativecarescotland.org.uk

Scottish Partnership for Palliative Care (2006) *Making Good Care Better – National practice statements for general palliative care in adult care homes in Scotland.* 1a Cambridge Street, Edinburgh EH1 2DY; tel 0131 229 0538; fax 0131 228 2967; website: www.palliativecarescotland.org.uk

Charities and support organisations

Alzheimer Scotland – Action on Dementia
22 Drumsheugh Gardens
Edinburgh EH3 7RN

Tel 0131 243 1453
Fax 0131 243 1450

Website: www.alzscot.org

British Heart Foundation
4 Shore Place
Edinburgh EH6 6UU

Tel 0131 555 5891
Fax 0131 555 5014

Website: www.bhf.org.uk/about

British Lung Foundation
Suite 2/2 Olympic House
142 Queen Street
Glasgow G1 3BU

Tel/fax 0141 229 0318

Website: www.lunguk.org/scotland

Cystic Fibrosis Trust
11 London Road
Bromley
Kent BR1 1BY

Tel 0204 464 7211
Fax 0208 313 0472

Website: www.cftrust.org.uk

Multiple Sclerosis Society Scotland
National Office
Ratho Park, 88 Glasgow Road
Ratho Station
Newbridge EH28 8PP

Tel 0131 335 4050
Fax 0131 335 4051

Website: www.mssocietyscotland.org.uk

Muscular Dystophy Campaign
PO Box 14813
Bonnybridge
Stirlingshire FK4 2YD

Tel/fax 01324 810958

Website: www.muscular-dystrophy.org

Parkinson's Disease Society Scotland
Forsyth House
Lommond Court
Castle Business Park
Stirling FK9 4TU

Tel/fax 01786 433811

Website: www.parkinsons.org.uk

Scottish Kidney Federation
Miss Alison Blezard
Scottish Kidney Federation
88 Muirhouse Drive
Edinburgh EH4 4TN

Tel 0131 336 5027

Scottish Motor Neurone Disease Association
76 Firhill Road
Glasgow G20 7BA

Tel 0141 945 1077
Fax 0141 945 2578

Website www.scotmnd.org.uk

Waverley Care Trust
58A Queen Street
Edinburgh EH2 3NS

Tel 0131 226 2206

Website: www.waverleycare.org

Appendix 6

Project team

Appendix 6: project team

Steering group members

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Maria McGill	Chief Executive, Highland Hospice and Deputy Chairman, Scottish Partnership for Palliative Care
Alison Poole	Project Manager, Scottish Partnership for Palliative Care
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Craig Stockton	Chief Executive, Scottish Motor Neurone Disease Association and Honorary Treasurer, Scottish Partnership for Palliative Care
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Alex Grant

Roy Green

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Dr Patricia Cantley	Consultant in Elderly Medicine, Liberton Hospital, Edinburgh

David Johnson	Director, Waverley Care Trust
Lawrie MacDougall	Cystic Fibrosis Nurse Specialist, Ninewells Hospital, Dundee
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Kitty Mason	Principal Planning and Commissioning Officer, Edinburgh City Council Social Work Department
Norma McIndoe	Multiple Sclerosis Nurse Specialist, Falkirk and District Royal Infirmary
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Yvonne Millerick	Clinical Nurse Specialist, Glasgow Heart Failure Liaison Service
Alison Poole	Project Manager, Scottish Partnership for Palliative Care
Yvonne Robb	Muscular Dystrophy Care Advisor, Muscular Dystrophy Campaign
Patricia Wallace	Director, Scottish Partnership for Palliative Care

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