

Making good care better

*National practice statements for general
palliative care in adult care homes in Scotland*



SCOTTISH EXECUTIVE



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May 2006

Foreword



Our population is ageing, more people are entering care homes, and many of these people are suffering from a life limiting illness. Increasingly, people want to see out their last days in familiar and homely surroundings: many people do not want to die in hospital. It is therefore important that our care homes in Scotland provide good palliative care.

These practice statements sit alongside the National Care Standards and replace the 1998 National Nursing Homes Scotland Core Standards for Palliative Care. They are set at a level that should be achievable by all care homes. As with the national care standards, these practice statements have been developed from the point of view of the person who uses the services. They describe what those living in care homes can expect from the service provider.

It is important that these statements result in good quality palliative care being delivered in care homes and drive excellence in service delivery. Their publication will make a real difference to service users now and in the future.

DR HARRY BURNS
Chief Medical Officer for Scotland

Preface



It is with great pleasure that I welcome new national practice statements for general palliative care in adult care homes. The biggest challenge and change of emphasis arising from these new statements is that all care homes will now be expected to deliver a palliative care approach for their residents, their family and friends.

These new statements will raise public awareness of palliative care, resulting in improved services and a greater say in decision making for service users and their families. It is crucial when considering how best to improve palliative care that those living in care homes have a say in determining what happens to them and are in a position to make both appropriate and informed decisions when faced with a life limiting illness.

The Care Commission, therefore, intends to recognise these new national palliative care practice statements as best practice when inspecting the quality of palliative care delivered in care homes. They will also be taken into account when registering any new care home and when investigating complaints or carrying out enforcement activity in adult care homes.

The palliative care practice statements set out what people can expect from their current or future care home in order to meet their palliative care needs. They will, equally importantly, provide a resource for care home owners and managers to help them deliver palliative care to both an acceptable and achievable level.

I very much hope that everyone, service users, their families and service providers will benefit from the implementation of these new palliative care practice statements and that they will lead to a meaningful improvement in the quality of palliative care throughout all adult care homes in Scotland.

JACQUIE ROBERTS
Chief Executive, Care Commission

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Introduction

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 person's 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.

As our population ages and more people live longer, more and more of us are likely to spend time towards the end of our lives in care homes. We are likely to have a number of different long-term and progressive medical conditions, and to have more complex needs than residents of care homes in the past. We will require general palliative care on a day-to-day basis.

Many care homes are already providing good general palliative care, even though the term may be unfamiliar to them. These practice statements, developed by the Scottish Partnership for Palliative Care at the request of the Scottish Executive, are designed to help them do it better.

What you need to know

What is palliative care?

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.

Palliative care can be provided at any stage after diagnosis of a life-limiting

illness or condition, but it has increasing importance 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

This 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. A palliative care 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 paid carers, volunteers, family or friends. You will find examples throughout these practice statements of ways to put a palliative care approach into practice in your care home.

General palliative care

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

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

General palliative care is provided for those who need it as part of normal care 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

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 multi-professional specialist palliative care teams and can be accessed in any care setting.

These practice statements are about the palliative care approach and general palliative care in care homes. They do not refer to the provision of specialist palliative care, except in relation to an understanding of when it is appropriate to seek specialist advice or a referral to specialist palliative care services.

Palliative care in care homes

It is now widely recognised that palliative care should be available to anyone with a life-limiting illness, regardless of diagnosis, and regardless of where the person is being cared for - whether in their own home, in a care home, or in a hospital.

Examples of life-limiting illnesses include cancer, diabetes, dementia, heart disease, kidney disease, lung disease, stroke and a range of progressive neurological conditions.

Older people increasingly choose to die in a care home, especially if it has been their home for the last few months / years. It is estimated that one in five of the UK population over the age of 65 years will end their life in a care home in the future. Many care home residents will have life-limiting illnesses, and these practice statements make clear that it is the responsibility of every care home provider to ensure that care home staff are able to follow the palliative care approach.

Following the introduction of the Regulation of Care (Scotland) Act 2001 there are now no legal differences between residential homes and nursing homes. They are all care homes and can be more flexible about the services they offer. They can meet all aspects of accommodation, support and care needs, including nursing care. Care homes which do not have nurses on the staff are not responsible for providing nursing care, but are responsible for accessing appropriate professional advice or help when they recognise a need that they cannot meet.

It is hoped that the introduction of these practice statements will mean that more and more care home residents have their palliative care needs recognised and met.

All care homes should be able to provide general palliative care.

For **care home owners and managers** this means ensuring that:

- staff are aware of and use a palliative care approach at all times when looking after residents with life-limiting illnesses
- staff understand how to get help and advice in providing general palliative care and recognise when this is required
- staff understand how to access specialist palliative care advice and specialised services where appropriate.

For **care home residents** this means:

- you can choose to move into a care home for the rest of your life
- staff in the home will be able to cater for your changing needs
- it may be possible to remain in your care home if you become ill or are dying.

What are the palliative care practice statements?

These palliative care practice statements describe what is involved in providing good palliative care in a care home. Each of the practice statements addresses distinct issues that are important when living in a care home.

The practice statements are endorsed by the Scottish Executive and the Care Commission as the standard to be aspired to and achieved in the provision of general palliative care in care homes. They are to be read and used alongside the Scottish Executive national care standards for adult services. Like them, they are written specifically for the service user. These practice statements are written and numbered on the basis of the national care standards for older people, but are appropriate to all types of adult care home, whether for older people, for those with learning disabilities or those with mental health problems.

Each statement has an introduction explaining its relevance to palliative care. The national standards are grouped under headings which follow the journey through the service. The statements retain these headings, but two of the standards, Standard 2 (Trial Visits) and Standard 4 (Your Environment), were not included in the palliative care statements because they required no additional comment.

Some issues, for example communication, are raised in more than one practice statement. This is because as key areas central to the provision of good quality palliative care, these issues were felt important enough to merit mention more than once.

Who are the practice statements for?

Care home residents have a right to expect a certain quality of service. The introduction of these practice statements clarifies for residents what that level of quality should be as regards the general palliative care provided in care homes. The practice statements will also help care home providers and managers to know what is expected from them and to develop their service in appropriate ways.

What are the principles behind the statements?

The statements are based on the same set of principles as those in the national care standards. They recognise that services must be accessible and suitable for

everyone who needs them, and must be based on respect for the principles of equality and diversity. The statements reflect the view that the experience of care home residents in receiving services is very important, and that this experience should be positive. They also reflect the right of residents to enjoy dignity, privacy, choice and safety, and to realise their potential.

How will the practice statements be used?

Future care home residents will want to refer to the palliative care practice statements as well as the appropriate national care standards for care homes to help decide which home to choose.

People already living in a care home may want to use the statements when discussing the care they receive with:

- care home staff and managers
- their social worker or care manager if they have one, or
- someone acting on their behalf, for example, a lawyer or other independent representative.

If things go wrong, residents may also wish to refer to the statements to help them raise concerns or make a complaint.

Care home owners and managers will use the statements to find out what is expected from them in providing palliative care. It is recognised that there are long-term training, education and resource implications for care home owners and managers in the introduction of these practice statements, and that full implementation will not be achieved overnight.

The practice statements focus on the quality of life that the person using the service actually experiences. The statements make it clear that everything about the service in a care home should ensure that residents with a life-limiting illness or condition should receive good quality palliative care.

A list of helpful resources and sources of information for care home owners and managers is provided as an appendix to the statements. The list includes guidance on:

- accessing specialist advice and equipment
- education and training of staff
- managing symptoms
- supporting residents and their families / friends around the time of and after death.

The Care Commission will use the statements as a standard of best practice, and will use them as part of routine monitoring and inspection to work with care homes to improve the quality of palliative care provided.

Why are there two levels?

The practice statements should result in improved quality of care for people with palliative care needs and are set at a level that can be achieved by all care homes. Some care homes have already had the opportunity to develop and provide a good standard of general palliative care, while others have not. By showing two levels, one describing good practice for those who have less experience in this area, and the other describing best practice for those with some experience who would like to improve, the practice statements provide guidance to both groups. They also reflect the fact that some residents will have more complex needs, and thus require more complex care, than others.

Good practice as identified in the statements should be available in every care home. Many care homes will already achieve or exceed this standard. Care Commission officers will encourage the rest to do so as soon as possible.

Best practice is intended to be stretching and is designed to help care home managers know what to do to continue improving the quality of palliative care provided in their home. All care homes should over time aspire to achieve the best practice statements. Some may already exceed these also.

Under some headings no additional best practice statements have been identified. This is because in these cases there is no distinction between good and best practice and so everything has been categorised as good practice. In order to achieve best practice all corresponding good practice statements will have been met.

The practice statements

Practice statement 1

Informing and deciding

Since it is possible that you will be able to remain in your care home until the end of your days, it is important to consider how a particular care home might be able to meet your needs if and when your health deteriorates towards the end of your life.

Care homes will have information on the palliative care they can offer which can help you make an informed choice about which home would best suit your needs. You may wish to discuss this at your trial visit.

Good practice

1. Staff in the care home will be aware of the palliative care approach (see appendix 1).
2. The home will have policies and procedures relating to the care of people with palliative care needs, including care at the end of life.
3. The care home staff will be familiar with the concept of 'living wills' (see appendix 1) and will know how to organise this for you if you wish. They will then work with you and / or your representative to ensure that your living will is followed wherever possible and will review it with you as appropriate.
4. At an appropriate point and in a sensitive manner, you will if you wish be given an opportunity to discuss your wishes for the end of your life so that you can clearly state what you would like to happen, including any preferred funeral arrangements. Your wishes will be recorded in your care plan. (see appendix 1).
5. Your GP, and possibly the primary health care team, (see appendix 1), will support you throughout your care. In the last days of your life care home staff will watch over you carefully and will spend as much time with you as possible if that is your wish.
6. If you wish for family or friends to help with your care or to be with you in the last days of life and this is possible, the care home will

facilitate this. (You may also wish to refer to practice statement 16, 3.)

7. Should you become incapacitated, you can be assured that care home staff will be familiar with your rights under the Adults with Incapacity (Scotland) Act 2000 (see appendix 1), and will act accordingly. (You may also wish to refer to practice statement 3, 3.)

Best practice

1. There will be an on-going programme of education / practice development (see appendix 1) in the palliative care approach for staff in all care homes.
2. Homes that provide nursing care will have at least one nurse on the staff who has a degree level qualification with modules in palliative care.

Practice statement 2

Trial visits

There is no palliative care practice statement relating to 'Trial visits' because the national care standard on this topic requires no additional comment relevant to palliative care.

Practice statement 3

Your legal rights

If you want to discuss your views and wishes about the end of your life, a member of staff will offer to do this with you, including discussing your rights to remain in the home. All staff will help you to meet those wishes that are achievable.

Good Practice

1. If it is felt that the care home can no longer meet your palliative care needs this will be fully discussed with you and / or your representative and with the primary health care team / specialist palliative care services to ensure all options have been explored before any decision to move you to a more suitable palliative care environment is made.
2. Care home staff will assist you in seeking help to settle any outstanding affairs (legal or otherwise) if you so wish.
3. You can be assured that the home is aware of your rights and their responsibility in relation to the Adults with Incapacity (Scotland) Act 2000, (see appendix 1) and will be able to show how they put this into practice.

Practice statement 4

Your environment

There is no palliative care practice statement relating to 'Your environment' because the national care standard on this topic requires no additional comment relevant to palliative care.

Practice statement 5

Management and staffing arrangements

In order that care home staff can meet your palliative care needs they will require an awareness of the palliative care approach (see appendix 1).

Good practice

1. All staff will have access to basic training in the palliative care approach.
2. Guidance is available for the care staff within your home on how to access all members of the primary health care team (see appendix 1) as well as specialist palliative care advice and services, and any other support necessary for your care.
3. Where appropriate, there is joint working between all the services involved in your care such as:
 - care home staff
 - chiropodists / podiatrists
 - clinical nurse specialists (eg diabetes nurse)
 - dieticians
 - mental health specialists
 - occupational therapists
 - pharmacists
 - physiotherapists
 - primary health care team (GP, district nurse etc)
 - religious or spiritual adviser
 - social workers
 - specialised care services (eg heart failure nurse, stoma nurse)
 - speech and language therapists.
4. Staff in your care home can regularly access guidance such as assessment tools used in palliative care. (Examples can be found at appendix 2.)

Best practice

1. In homes providing nursing care, at least one member of the registered nursing staff should have a degree level qualification which includes modules in palliative care.
2. Care staff at your home have, or are working towards, a palliative care qualification eg SVQ Level 3 or equivalent. (Please refer to appendix 2 if you require further information).
3. Volunteers at the care home who work directly with you have received education and training in palliative care.

Practice statement 6

Support arrangements

If you are considering moving to a care home any existing and possible future palliative care needs will be discussed and included in your personal plan.

Good practice

1. At least one member of staff should be:
 - familiar with the palliative care approach (see appendix 1)
 - aware of your preferences about your end-of-life care
 - competent in communicating with:
 - you and those close to you
 - other care home staff
 - other professionals involved in your care
 - aware of and able to use effective ways of identifying any problems you may have, including pain (Please refer to appendix 2 for examples of assessment methods). The staff from the home should make sure that they are using the same assessment methods as your local support services (see appendix 1).
 - aware of what each member of your local support services can do to make sure your needs are being met and how to access these services. They will contact services on your behalf if you require.
 - aware of what sources of specialist palliative care advice are available locally and how to access local specialised care services (see appendix 1). They will contact the services on your behalf.
2. Arrangements for accessing local support services, specialist palliative care and other services will be contained within the care homes policies and procedures.
3. The member of staff (key worker) who is responsible for developing your personal plan with you must have the skills,

knowledge and confidence to discuss your:

- individual health care needs
- communication needs
- social needs
- spiritual needs.

As your needs change they will be monitored and reviewed and your personal plan adjusted with your involvement. This may need to be done very frequently.

Best practice

1. At least one member of staff per shift will be able to do everything detailed in 1 and 3 above.
2. Staff will recognise when you are approaching the end of your life and will be able to take part in the use of an 'integrated care pathway' (see appendix 1 and appendix 2 for further information) to guide your care. This will be arranged between care home staff and your GP / district nurse.

Practice statement 7

Moving in

When you move into a care home, it is very important that you feel that any existing and any future palliative care needs you may have will be met.

Good practice

1. If your palliative care needs are identified before you move in, you and/or your representative will have an early opportunity to discuss these with your key worker who will explain to you how they are going to be met.
2. At the time of moving into the home, you will be given the opportunity to identify a relative, friend or other individual whom you would like to act as your legal representative in the event that you become incapacitated while in the home. This information will be recorded in your care plan and reviewed with you regularly. (You may wish to refer to practice statement 3 also.)

Practice statement 8

Making choices

Your wishes and choices about the kind of care you would prefer towards the end of your life should be included in your personal plan. This may include a living will.

Should you choose to remain in the care home, and this is possible, you will have the right to receive the appropriate level of skilled care. This may include requesting additional help from support services.

Good practice

1. Members of staff who are responsible for helping you to make your choices must have the skills, knowledge and confidence to discuss these. This means that at least one member of staff should be:
 - familiar with the palliative care approach
 - aware of your preferences about your end-of-life care
 - competent in communicating with:
 - you and those close to you
 - other care home staff
 - other professionals
 - aware of the roles and responsibilities of other professionals within local support services and specialised palliative care services
 - able to act as advocate, if required, to access local support services, specialist palliative care and other specialised services (you might wish to refer to practice statement 6 for more information)
 - able to support you in deciding whether or not to have a living will (see appendix 1) and to guide you to appropriate help in putting this in place should you so decide. (You may wish to refer to practice statements 1 and 3 also.)
2. In order for your choices to be met it will be important for the staff within the home to discuss them with each other and other relevant members of your support team.
3. Whenever you express a choice, the member of staff you are

discussing this with will check whether you are happy for this to be shared with others. This will include documenting and reviewing your choices in your personal plan.

Best practice

1. Your choices concerning your care during your last few days of life will be reviewed with you regularly by a member of staff trained in communication and counselling skills. This includes any preferences around what should happen following your death.

Practice statement 9

Feeling safe and secure

The care home will aim to make you feel safe and secure at all times, and especially in the last few days or weeks of your life.

Good practice

1. You can be confident that you can express any fears or anxieties you may have to care home staff, and that these will be sensitively listened to and acted upon. Care home staff will seek the advice of your primary care team, local support services, local specialist palliative care services and other specialised services as appropriate.
2. The care home will have a policy of dealing with symptoms of agitation or restlessness which makes clear the importance of seeking medical advice to assess the cause of these.
3. In a home that provides nursing care, you can be sure that the registered nursing staff understand the uses of medication to help alleviate restlessness or agitation, particularly in the last few days or weeks of life.

Best practice

1. In a home that provides nursing care, you can be sure that the registered nursing staff understand the use of methods other than medication to help alleviate restlessness or agitation, particularly in the last few days or weeks of life.

Practice statement 10

Exercising your rights

When you have palliative care needs you may wish to focus on your spiritual, religious and faith needs when considering exercising your rights. You may wish to look at practice statement 12 for more detail to help you with this.

Practice statement 11

Expressing your views

If you have concerns about how the care home can meet your palliative care needs, you will be able to discuss these freely with care home staff. You can also be confident that staff will listen and act accordingly.

Good practice

1. All care home staff will have an awareness of the palliative care approach. They will listen sensitively to your concerns and will know how to act upon them.
2. If you are unable to express your views about your palliative care needs as you would wish, you will be assisted in seeking advocacy support to identify someone to speak on your behalf.
3. In addition to independent advocacy, the care home will also be able to direct you / your family to a range of support organisations which can provide information about living with specific medical conditions such as arthritis, Alzheimer's disease, dementia, diabetes, cancer, heart and lung disease, learning disability, Parkinson's disease etc, which may result in palliative care needs. (see appendix 2)

Practice statement 12

Lifestyle - social, cultural and religious belief or faith

If you have palliative care needs, this may change the way you live your life. Staff will recognise this and will help you to cope by discussing your feelings and the implications of these changes with you.

They will also assist with helping you to follow your social, personal and cultural beliefs and to meet any needs associated with these. (You may wish to look at practice statement 19 for more detail to help you with this).

Should you wish, you will continue to be included in the social life of the home for as long as you are able, and helped to continue with your close relationships.

Good practice

1. The care home will have access to someone with the skills knowledge and confidence to discuss your social, cultural, faith and lifestyle preferences with you should you wish to do so.
2. Care home staff will be aware of how to get in touch with the people who can support you with your cultural, faith and lifestyle preferences.
3. If you require help to follow your chosen religious or spiritual practices, and if staff are unfamiliar with your particular faith, they will find out how to help you. (see appendix 2)

Best practice

There will be one member of staff within the home who can support you if you require help to follow your chosen religious or spiritual practices. Examples of this might be someone who could say a prayer with you or read a particular text to you if you wish.

Practice statement 13

Eating well

Your medical condition may affect your appetite for food and drink. Should this happen, the care home will respond appropriately to your needs and preferences.

Good practice

1. If you no longer want or need to eat or drink so much, staff will know the importance of offering small amounts of tasty food / drinks according to your preferences.
2. Drinks and snacks will be available for you at all times during the day and night.
3. If you need help to eat, one person will stay with you and assist only you throughout your meal. This could include family, friends or volunteers as well as care home staff.
4. Those assisting you to eat will have the necessary knowledge and skills to maintain your comfort, dignity and safety.
5. Care home staff will help you to keep your mouth clean, fresh and comfortable.
6. The chef / cook will be aware that certain medical conditions (eg cancer, dementia) can alter taste and smell and will provide a variety of individual, flavoursome food.
7. The chef / cook will also recognise that certain medical conditions may require a special diet suited to your needs. Food such as different textured diets will be provided to meet such needs.
8. Procedures to monitor your nutrition such as regular weighing will be discontinued when no longer necessary to your wellbeing.

9. If you have made known any specific wishes regarding eating or feeding (eg tube feeding, see appendix 1) via a living will or other means this will be respected by those caring for you.

Best practice

1. The care home chef / cook will discuss with you, and if appropriate your dietician, any changing needs for food caused by your medical condition.
2. Nutritional drinks made from fresh ingredients to supplement dietary needs will be made available to you.
3. Any textured diets required will resemble the food presented (eg using moulds) to improve presentation of food.

Practice statement 14

Keeping well - healthcare

It is important that you are enabled to keep as well as possible throughout your stay in the care home, and that particularly in the last few days and weeks of your life when the focus of care will be on your palliative care needs, you should be as comfortable as possible.

Good practice

1. You can be confident that care home staff will:
 - assess your condition as often as necessary, recording this in your care plan and taking any necessary action promptly
 - be able to recognise your physical, social, psychological and spiritual care needs
 - have protocols in place to ensure that they access staff with the appropriate skills and knowledge to meet these needs, including accessing your GP / district nurse or specialised care services (see appendix 1)
 - have protocols in place to ensure that they access any appropriate equipment required to meet your needs.
2. You, and if you wish the people closest to you, will be fully involved in the continuing development of your care plan.
3. You, and if you wish the people closest to you, will be kept as informed as you wish of the details of your care and the progression of your condition.
4. Staff will maintain contact with those closest to you and offer them support in the last days of your life.

Best practice

1. In homes providing nursing care you can be confident that registered nursing staff will have the appropriate skills and knowledge to manage the symptoms of your illness and will work with your primary health care team, local support services and local

specialised care services to ensure that you receive appropriate care. (You may wish to look at Practice statement 5 for more detail on what this means)

2. The staff responsible for your care will make full use of appropriate methods for assessing symptoms such as pain. (Please refer to appendix 2 if you require further information).

Practice statement 15

Keeping well - medication

It is possible that your palliative care and / or end of life care needs may be met without the use of any medication. However, if you have any symptoms which are troubling you, the use of appropriate medication may be important.

There are times in palliative care when some medicines are used for reasons other than those for which they are normally prescribed, eg anti-depressants can help to ease some types of pain. When you are given new medicines their use will be explained to you.

Good practice

1. If you are unable to tell the care home staff that you have pain or other symptoms, they will be able to tell whether you are likely to have such symptoms and will report this to your doctor. (See practice statements 5 and 14.)
2. Whenever you are given a new medication, staff will explain to you what it is for. Some medications you may require are known to have side-effects, and other medication will need to be prescribed for you at the same time to prevent these side-effects. For example, if you are prescribed any strong pain-killing medication, this can often cause constipation and you will probably also be given a laxative.
3. Should your medication require to be changed urgently, or you can no longer take your medicines by mouth, you can be sure that staff will have locally agreed procedures to access:
 - medication out-of-hours
 - necessary equipment (see appendix 2)
 - appropriately qualified staff.
4. If you have difficulty taking your medication you can expect care home staff to recognise this and to seek alternatives from your GP / pharmacist. For example you may find liquids easier to swallow than tablets.

Best practice

In homes providing nursing care at least one member of registered nursing staff will be knowledgeable about the differing medications used in palliative care and end of life care.

Practice statement 16

Private life

At all stages of your life you have a right to be treated with dignity and to have your privacy respected. This will not change when you live in a care home or as the end of your life approaches.

Your wishes to have familiar people with you or not (for example relatives, friends, clergy or members of staff) will be respected. You will be able to spend time with these people in private if you wish.

Staff will balance the need for physical care or treatment whilst respecting your individual needs for comfort, reassurance and security.

Good practice

1. Your right to be treated with dignity and to have your privacy respected will be maintained throughout your stay in the care home right up until your death.
2. Staff in the home will know or will find out from you the people that are important to you. With your permission these people will be kept informed of your wellbeing. This will be done in private.
3. Provision will be made for relatives or friends to be accommodated overnight in the care home in order that they can be with you at the end of your life if that is your and their wish. This will include facilities for sleeping, eating and washing.

Practice statement 17

Daily life

If your health deteriorates towards the end of your life and your daily life changes as a result, staff will continue to include you in the routine life of the home for as long as you wish and are able.

Good practice

1. Care home staff will be able to assess and take responsibility for reporting to your GP any symptoms (such as pain, distress, agitation, constipation) which may be affecting the quality of your daily life.
2. Care staff will be trained to a basic level in listening skills and will discuss with you any concerns you have about the quality of your daily life.
3. You may have specific needs related to your condition. Staff will ensure they have information about organisations which focus on specific conditions that might be better able to give you information and advice. (See appendix 2 for some examples of these.)
4. With your permission care staff will explain to other residents when you are less well so that they will be able to comply with your wishes about if or when you see other people within the home.

Practice statement 18

Staying in touch

It is possible that your ability to communicate may change at some point as a result of deteriorating health or a specific medical condition. Staff in the care home will be aware of this. They will assist you, and support you where necessary, in keeping in touch with those who are important to you.

Good practice

1. Staff will recognise that physical or emotional difficulties may affect your ability to communicate or keep in touch with people. If this happens, they will seek help from your primary health care team or local support services to manage these if necessary.
2. Anyone who normally helps you with any communication difficulties (eg key worker, support worker, interpreter) will be made aware of the effect of any change which affects your ability to communicate in order to help them meet your needs.
3. If the staff believe your death is close they will tell the person or people who are important to you if this is your wish. This will include those in the care home with whom you have built up a friendship. If you and they wish, those close to you can be with you at this time.

Practice statement 19

Support and care in dying and death

Care home staff will continue to respect and value you as a unique individual in the days leading up to your death, and will care for you accordingly.

Good practice

1. You can expect that your physical needs will be met and your symptoms controlled when you are dying. Staff will be able to:
 - access your primary health care team (eg GP and district nurse)
 - call appropriate advice and support when you need it
 - acquire and safely use additional equipment that may be needed for your comfort. (Please refer to appendix 2 if you require further information on suggested equipment.)
2. Care staff will ask you about your spiritual and religious needs and will assist you in having these met if you wish. (You may wish to refer to Practice statement 12 also.)
3. Staff will have an awareness of the different meanings that spirituality has for people. At least one member of staff will have basic training in issues around death and dying.
4. The staff will be aware of the effect of bereavement on your relatives, and where necessary, will provide appropriate information and support leading up to and around the time of your death. They will offer copies of the booklet 'What to do after a death in Scotland' (see appendix 1) to the people closest to you.
5. The care home will have a policy allowing nurses, once they have had appropriate training, to confirm deaths that GPs have considered likely to happen. This will mean that, if your death is expected, these nurses can inform your family / those closest to you of your death as soon as possible after it happens.
6. Staff at the care home will tell your fellow residents of your death in

a sensitive manner and will offer them appropriate support for as long as required.

Best practice

1. At least one member of staff has had appropriate training in loss, death and bereavement.
2. When staff recognise that someone close to you is likely to be significantly affected by your death, they will offer them information on appropriate sources of bereavement support. (Please refer to appendix 2 for further information.)
3. If your doctor is participating in systems to improve palliative care and the co-ordination of care (such as the Gold Standards Framework Scotland - see appendix 2) your care home will also follow these systems.
4. The care home will have a process for ensuring that your care needs are met in the last few days of life eg by following an integrated care pathway (see appendix 1) such as the Liverpool Care Pathway. (Please refer to appendix 2 for further information.)

Practice statement 20

Moving on

If your health deteriorates and you need particular types of specialist care, 'moving on' may mean moving to another care setting. If you are in the last few days or weeks of your life, 'moving on' may in fact mean dying. Staff will recognise that both of these circumstances may lead to increased anxiety and will care for you appropriately.

Good practice

1. Staff will give you the opportunity to express your thoughts and feelings. They will also help you to make contact with any additional support you may require.
2. Staff will explore with you any wish or need you have to move to another care setting. They will involve members of your primary health care team, local support services, local specialist palliative care services or other specialised services as needed to discuss the possibility of this happening. You and your family / those closest to you will be included in all discussions about a possible move.

Appendix I: glossary of terms

Advance directive / Advance statement

See Living will

Advocacy

The representation of a person's views or interests by a third party, especially when the person is unable to express or represent themselves. (See Independent advocacy services)

Assessment

The process of identifying and measuring someone's needs, or of collecting and reviewing information in order to make a decision or judgement about something.

Assessment methods

Ways in which assessment is carried out. May include using sets of questions or forms that have been devised to collect information about specific things, eg pain assessment tools may include forms asking questions about pain.

Capacity / Incapacity

Having capacity means that a person is able to make decisions; incapacity refers to the loss in some way or another of this ability. People can have varying levels of capacity and may have capacity for some things and not for others. The Adults with Incapacity (Scotland) Act 2000 (see appendix 2) outlines how to make decisions on behalf of people who do not have capacity.

Cardio-pulmonary resuscitation (CPR)

A physical technique used to try to keep a person alive when their breathing or heart-beat stops. Basic CPR is a combination of blowing breaths through the affected person's mouth and compressing on their chest. This should only be carried out by people who have had training in this technique (eg as part of first aid training). Advanced CPR uses medical and electrical equipment and is only carried out where this is available (such as hospitals and ambulances) by specially qualified people (such as doctors and paramedics).

Care plan

A document which details the care and treatment that a person receives and identifies who delivers the care and treatment. Your care plan may be part of your personal plan and indicates to care staff how to meet your care needs. (See Personal plan)

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 usually unpaid. Paid staff in care homes may also be called carers.

Complex needs

Needs that cannot be addressed through simple or routine methods or care.

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 appendix 2 and Terminal care below.)

GP

General Practitioner. Used to be known as a 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 below and appendix 2).

Independent advocacy services

Services which help people who find it difficult to express their wishes or concerns to say what they want. This may include getting information for them about options that are available to them, representing their interests, or obtaining for them the services they need. Advocacy services are independent from statutory organisations. (See Advocacy)

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. For an example, see the Liverpool Care Pathway for the Dying Patient (see appendix 2).

Key worker

The member of staff in the care home who is the first point of contact for an individual resident and who is responsible for co-ordinating the care required by that person and ensuring that needs are met.

Life-limiting illness

An illness which is no longer curable and which is likely to progress and lead to death.

Living will

Also called 'advance directive' or 'advance statement'. A signed, written statement made by a person while they are competent (have capacity), detailing how they wish to be treated if, in time, they become unable to express their wishes for any reason. A living will is not legally binding but is taken into account by all members of the healthcare team.

Medication

A substance administered for treatment purposes.

Multidisciplinary

A multidisciplinary team is 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 medical care outwith what are regarded as normal working hours, ie between the hours of 5pm and 9am 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 health 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 to address social, emotional and spiritual needs. (See General palliative care, Palliative care approach, Specialist palliative care and appendix 2)

Palliative care approach

A person-centred and holistic approach to care which is based on palliative care principles. (See General palliative care, Palliative care, Specialist palliative care and appendix 2)

Personal plan

A plan based on an individual's need for care, detailing how support and care services will be provided and agreed between that individual and the service provider. May also be known as a 'care plan' or 'plan of care' or may include these. (See Care plan)

Pharmacist

A qualified professional who understands how medicines are produced and used to prevent and treat illness, relieve symptoms or assist in the diagnosis of disease.

Practice development

Actions taken by managers to keep staff teams updated in skills and knowledge in order to develop the best practice and to provide the best service possible. The provision of on-going education and training for individual staff and the sharing of good practice across the organisation as a whole are important examples of practice development.

Primary health care team

Primary care is healthcare delivered outside hospitals, usually by general practices. The primary healthcare team is 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. Examples include some heart and lung diseases and neurological conditions such as dementia.

Quality of life

Term used to describe the overall assessment of a person's situation and their sense of personal well-being.

Registered nurse

A nurse is a person who is specially trained to provide services that are essential to or helpful in the promotion, treatment, maintenance and restoration of health and well-being. A registered nurse is one who has undergone a lengthy period of training in order to gain a qualification in nursing and who is registered with the United Kingdom's Nursing & Midwifery Council.

Representative

A person acting on behalf of another person, who may be a relative or friend.

Resuscitation

Restoration of life or consciousness to someone who has collapsed or stopped breathing. (See also Cardio-pulmonary resuscitation.)

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 professional 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 and is often a person's first point of contact when trying to arrange a care home placement.

Specialised care

The provision of particular forms of care appropriate to specific conditions and situations by a suitably qualified or trained specialist (eg diabetes clinical nurse specialist, heart failure nurse).

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. Care home staff can access local specialist palliative care services if required to support the provision of appropriate palliative care. (See appendix 2 for more details.)

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. (See appendix 2.)

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 stage of an illness, with the emphasis on relief of symptoms in order to allow the person to feel as comfortable as possible.

Tube feeding

The provision of nutrition through a tube which can be used if a person has difficulties with or becomes unable to eat or drink.

'What to do after a death in Scotland'

Free booklet produced by the Scottish Executive explaining the legal and other procedures to be followed after someone has died. (See appendix 2.)

WHO

World Health Organization. A United Nations agency dealing with issues concerning health and disease around the globe. (See appendix 2 for WHO definitions of palliative care.)

Appendix 2: additional information and resources for care home staff

INDEX:

Additional reading
Adults with Incapacity (Scotland) Act 2000
Bereavement care
Charities and support organisations
Cultures and beliefs
Education, training and qualifications
Equipment
Gold Standards Framework
Good practice guidance
Integrated care pathways
Liverpool Care Pathway
Medicines
National Care Standards
Pain assessment
Palliative care
Pharmacy
Regulation of Care (Scotland) Act 2001
Special notes
Spiritual care

ADDITIONAL READING

The following reading list about different aspects of palliative care may be useful:

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

Clinical Standards Board for Scotland (CSBS) (2002) *Clinical Standards: Specialist Palliative Care* NHS Quality Improvement Scotland, Elliott House, 8-10 Hillside Crescent, Edinburgh EH7 5EA; tel 0131 623 4300; email: comments@nhshealthquality.org or search publications on the website: www.nhshealthquality.org/nhsqis

Common Knowledge, Scottish Partnership for Palliative Care and St Columba's Hospice (2003) *Palliative Care and People with Learning Disabilities* Scottish Partnership for Palliative Care, 1a Cambridge Street, Edinburgh EH1 2DY; tel 0131 229 0538; website: www.palliativecarescotland.org.uk

Ellershaw J & Wilkinson S (2003) *Care of the Dying: A Pathway to Excellence* Oxford, Oxford University Press. (This is the key textbook about the Liverpool Care Pathway for the Dying.)

Dr Katherine Froggatt (2004) *Palliative Care in Care homes for Older People* National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS; tel 020 7697 1520; email: enquiries@ncpc.org.uk website: www.ncpc.org.uk

General Medical Council (1998) *Seeking Patients' Consent: the Ethical Consideration* website: www.gmc-uk.org/publications/index.asp

General Medical Council (2000) *Confidentiality: Protecting and Providing Information* website: www.gmc-uk.org/publications/index.asp

Hockley J & Clark D (2002) *Palliative Care for Older People in Care Homes* Open University Press: Buckinghamshire.

Hockley J, Dewar B & Watson J (2004) *Developing quality end of life care in eight independent nursing homes through the implementation of an integrated care pathway for the last days of life*. This document reports the results of implementing the Liverpool Care Pathway in eight nursing homes and was part of the 'Bridges Initiative'. It can be downloaded from the website of St. Columba's Hospice, 15 Boswall Road, Edinburgh EH5 3RW; tel: 0131 551 1381 www.stcolumbushospice.org.uk

Komaromy C, Sidell M, Katz J S, (2000) *The quality of terminal care in residential and nursing homes* International Journal of Palliative Nursing, Vol.6 (4) 192-200.

National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) (1997) *Changing Gear: Guidelines for Managing the Last Days of Life - The Research Evidence* Clinical Guidelines Working Party, National Council for Hospice and Specialist Palliative Care Services: London. National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS; tel: 020 7697 1520; email: enquiries@ncpc.org.uk website: www.ncpc.org.uk

National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) / Scottish Partnership Agency for Palliative and Cancer Care (2000) *Positive Partnerships: palliative care for adults with severe mental health problems* NSHSPCS, London. National Council for Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS; tel: 020 7697 1520; email: enquiries@ncpc.org.uk website: www.ncpc.org.uk

Parkes CM (1990), *Risk factors in bereavement: implications for the prevention and treatment of pathologic grief* Psychiatric Annals 20, pp308-313.

Ross MM, Fisher R & Maclean M J (2000) *End-of-life care for seniors: the development of a national guide* Journal of Palliative Care 15 (4), pp47-53.

Scottish Executive (2006) *What to do After a Death in Scotland: Practical Advice for the Times of Bereavement, 7th edition*. Available free of charge from: Civil Law Division, Justice Department, 2 WR, Scottish Executive, St Andrews House, Edinburgh EH1 3DG; tel: 08457 741741 (UK local rate).

Teno JM (2003) *Now is the time to embrace nursing homes as a place of care for dying persons* Journal of Palliative Medicine 6 (2), pp293-6.

Thomas K (2003) *Care for the Dying at Home, Companions on the Journey* Radcliffe Medical Press: Oxford. (This is the official textbook of the Gold Standards Framework.)

World Health Organization (WHO), (2002) *The WHO definition of palliative care* United Nations, New York; website: www.who.int/cancer/palliative/definition/en/

ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

This Act has implications for the care of people in care homes who are or become incapacitated. For the purposes of the Act, 'incapacity' means being incapable of:

- acting
- making decisions
- communicating decisions
- understanding decisions, or
- retaining the memory of decisions

because of mental disorder or being unable to communicate because of physical disability.

The emphasis in the Act is on enhancing the individual's capacity wherever possible.

Under the Act anything that is done on behalf of an adult with incapacity will have to:

- benefit her or him
- take account of the person's wishes and those of her or his nearest relative, carer, guardian or attorney
- achieve the desired purpose without unduly limiting the person's freedom.

See *The Adults With Incapacity (Scotland) Act 2000* Edinburgh, Scottish Executive; available from: Blackwells Book Shop, 53/62 South Bridge, Edinburgh EH1 1YS; tel: 0131 622 8283; fax: 0131 622 8149; email: business.edinburgh@blackwells.co.uk
website: www.scotland.gov.uk/Publications/Recent

BEREAVEMENT CARE

Bereavement care is an important component of the palliative care approach and in care homes may be relevant to residents and staff as well as those people close to the person who has died. The important thing in bereavement care is allowing people who are feeling grief to express it and talk about the person who has died in their own way.

There are recognised factors which make some people at greater risk of being unable to cope with bereavement. These include:

- feelings about and preparation for death
- previous, or multiple, bereavements and difficulty coping with these
- lack of available support
- health or psychological problems and
- dealing with another life crisis at the same time.

Specialists can use risk assessment tools to help decide when someone is likely to be unable to cope with bereavement (see Parkes CM (1990) in Additional Reading above). Your local specialist palliative care services may be able to advise, and the organisation Cruse Bereavement Care (see Charities and Support Organisations below) may be able to provide information, training or support.

CHARITIES AND SUPPORT ORGANISATIONS

The following national charities and support organisations provide information on specific conditions and may be able to indicate further sources of help and advice:

Alzheimer Scotland - Action on Dementia

22 Drumsheugh Gardens
Edinburgh EH3 7RN
tel 0131 243 1453
fax 0131 243 1450
website: www.alzscot.org

Arthritis Care in Scotland

Unit 25a
Anniesland Business Park
Glasgow G13 1EU
tel 0141 954 7776
fax 0141 954 6171
website: www.arthritiscare.org.uk/home/index.cfm?region=scotland

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 Scotland

Suite 2/2 Olympic House
142 Queen Street
Glasgow G1 3BU
tel / fax 0141 229 0318
website: www.lunguk.org/scotland

Cancerbackup

Suite 2, 3rd Floor
Cranston House
104/114 Argyle Street
Glasgow G2 8BH
tel 0141 223 7676
fax 0141 248 8422
website: www.cancerbackup.org.uk

Chest, Heart & Stroke Scotland

65 North Castle Street
Edinburgh EH2 3LT
tel 0131 225 4800
fax 0131 220 6313
website: www.chss.org.uk

Cruse Bereavement Care Scotland

Riverview House
Friarton Road
Perth PH2 8DF
tel 0131 623 4300
email: info@crusescotland.org.uk
website: www.crusebereavementcare.org.uk

ENABLE Scotland

(Leading the way in learning disability in Scotland)
6th Floor, 7 Buchanan Street
Glasgow G1 3HL
tel 0141 226 4541
fax 0141 204 4398
website: www.enable.org.uk

Macmillan Cancer Support

Osborne House
1-5 Osborne Terrace
Edinburgh EH12 5HG
Tel 0131 346 5346
Fax 0131 3465347
website: www.macmillan.org.uk

Marie Curie Cancer Care

29 Albany Street
Edinburgh EH1 3QN
Tel 0131 456 3700
Fax 0131 456 3701
website: www.mariecurie.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

Parkinson's Disease Society

Forsyth House
Lommond Court
Castle Business Park
Stirling FK9 4TU
Tel/Fax 01786 433811
website: www.parkinsons.org.uk

Scottish Consortium for Learning Disability

The Adelphi Centre, Room 16
12 Commercial Road
Glasgow G5 0PQ
Tel 0141 418 5420
Fax 0141 429 1142
website: www.sclld.org.uk

Scottish Huntington's Association

Thistle House,
61 Main Road,
Elderslie PA5 9BA
Tel 01505 322245
Fax 01505 382980
website: www.hdscotland.org/index.php

Scottish Motor Neurone Disease Association

76 Firhill Road
GLASGOW G20 7BA
Tel 0141 945 1077
Fax 0141 945 2578
website: www.scotmnd.org.uk

CULTURES AND BELIEFS

Different religions and cultures have different customs, beliefs and practices surrounding caring for people who may be dying and the care that is provided after death. Care homes may need to be aware of some of these in order to respect individual difference and care for people appropriately.

(See Jogee M and Lal S (1999) 5th edition *Religion and Cultures – A Guide to Patients' Beliefs and Customs for Health Staff and Social Care Services*, Edinburgh Religions & Cultures Publications, P.O. Box 28420, Edinburgh, EH4 1XB;
email: matthew@randc.fsnet.co.uk)

EDUCATION, TRAINING AND QUALIFICATIONS

With reference to the National Care Standards, the Care Commission expects a learning culture to exist in care homes, with opportunities for education and training open to care home staff. This should include learning at an appropriate level about palliative care.

These practice statements require that all care home staff should be aware of the palliative care approach. To ensure education and training covers all aspects of this, the following areas

should be covered:

- communication and basic counselling skills, such as effective listening
- issues around death and dying
- understanding spirituality
- loss, death and bereavement
- pain and symptom assessment
- care in the last days of life, including use of syringe drivers (appropriate for registered nurses only).

There is a range of education and training in palliative care currently available in different parts of Scotland to address these issues. Most hospices provide education and training in palliative care. Short courses or study days specifically for care home staff may be provided by local colleges or universities or by some local hospices. It may be possible to arrange for these events to be held informally within the care home. There may also be palliative care courses or training days available locally for care assistants or for health and social care staff working in different settings which may be suitable.

Your local hospice or specialist palliative care service, or the health and community care department of your local college may be able to advise on what is available locally and on how to begin these learning processes. The Scottish Partnership for Palliative Care also produces a list of day conferences and short courses, with contact details and information on which groups of staff each event is suitable for. The list, *Courses and Conferences*, is available on the Partnership website at www.palliativecarescotland.org.uk or from Scottish Partnership for Palliative Care, 1a Cambridge Street, Edinburgh EH1 2DY tel 0131 229 0538. The website also provides contact details of all the specialist palliative care units and hospices in Scotland.

Some longer courses leading to qualifications at various levels are also available.

For registered nurses, courses leading to qualifications under the Scottish Credit Qualifications Framework (SCQF) may be available via local hospices and universities. These may include topics such as care of the elderly, communication and counselling skills, and management of pain and other symptoms. Many of these can be taken by care home staff as single modules rather than as part of longer courses. First degree level and Masters degree courses including module(s) in palliative care are also available and may lead to the award of a Specialist Practitioner Qualification.

For care assistants, modules in topics such as end of life care, or living at the end of life, may be available from some providers. In addition, the following Scottish Vocational Qualification (SVQ) Units may be appropriate:

- Care Levels 2 & 3: Unit Z8, support individuals when they are distressed
- Care Levels 2 & 3: Unit Z15, contribute to the care of a deceased person
- Care Level 3: Unit NC3, support individuals and others through the process of dying
- Care Level 4: Unit NC1, enable individuals, their family and friends to adjust to and manage their loss
- Care Level 4: Registered manager in health and social care.

Information about SVQs is available from the Scottish Qualifications Authority, Hanover House, 24 Douglas Street, Glasgow G2 7NQ; tel customer contact centre: 0845 2799 1000;

email enquiries: customer@sqa.org.uk

For care homes that are able to find a suitable person to lead training sessions, Macmillan Cancer Support has produced *Foundations in palliative care: a programme of facilitated learning for care home staff*. This training pack includes participant workbooks and a facilitator's manual, and covers principles of palliative care, communication, pain and symptom management and bereavement care. It is available from the Macmillan Resources Line on 01344 350310 or can be ordered online at www.professionalresources.org.uk/macmillan. The first copy is free to care homes, and subsequent copies are £30 each.

EQUIPMENT

There is now a range of equipment available that can be used outside of hospitals or hospices to support the provision of palliative care in someone's own home or in a care home. These items may include:

- drip stand
- electric fan
- naso-gastric feeding pump
- oxygen
- portable nebuliser
- pressure relieving equipment
- recliner chair
- suction machine
- syringe drivers (a device for the continuous delivery of pain relieving medicine: note that these may only be operated by qualified nurses trained in their use)

It is not necessary that every care home owns all of these, but care homes are likely to have some, such as electric fans and recliner chairs, already. You should have local arrangements in place to borrow additional items from other sources when required. Your District Nursing Service or local Joint Equipment Store should be able to help, and your local specialist palliative care service may also be able to offer short-term equipment loans. Note that training may be required in the use of these items, and you should discuss this when arrangements are made.

GOLD STANDARDS FRAMEWORK

The Gold Standards Framework (known in Scotland as the Gold Standards Framework Scotland or GSFS) is a UK-wide system for optional use by primary healthcare teams to improve the coordination and quality of palliative care services for people living in their own home or in a care home. It identifies people with palliative care needs and focuses on making simple improvements in planning and communication between health professionals to meet those needs. For example, for someone in a care home, a regular meeting could be held with the GP and / or district nurse where appropriate to plan and review the care provided.

The GSFS benefits everybody - patients, carers and health care professionals by:

- encouraging consistently good quality care for patients in their chosen environment
- acknowledging the role played by carers and supporting them with relevant information
- improving team work and confidence amongst staff.

The basic elements of the GSFS, seen as crucial to effective palliative care, are:

- communication
- co-ordination of care
- control of symptoms
- continuity out-of hours
- continued learning
- carer support
- care of the dying.

These are often referred to within the framework as the '7Cs'.

The framework is all-inclusive and includes all patients with palliative care needs, not just those with a cancer diagnosis. Additional information on the Gold Standards Framework can be found at the following website: www.goldstandardsframework.nhs.uk (See also Thomas K (2003) in the Additional reading list.)

GOOD PRACTICE GUIDANCE

In recent years attempts have been made in the NHS to encourage the sharing of good practice and to reach agreement on what actually constitutes good practice in different areas of clinical care. As a result a number of documents have been produced by the appropriate agencies, based on widespread evidence, discussion and consultation, to provide guidance on the best way to provide care in different situations. They are a useful benchmark with which to compare your own services, especially when auditing, developing or changing the services you offer. The examples below point to ways in which the highest quality of palliative care may be delivered:

Best Practice Statements (various) NHS Quality Improvement Scotland (NHS QIS) website: www.nhshealthquality.org/nhsqis NHS QIS, Elliott House, 8-10 Hillside Crescent, Edinburgh EH7 5EA; tel 0131 623 4300; email: comments@nhshealthquality.org

Better Outcomes for Older People - Framework for Joint Services for Older People, (2004) Scottish Executive, Edinburgh; website: www.scotland.gov.uk/Publications/Recent

Food, Fluid and Nutritional Care in Hospitals (2003), NHS Quality Improvement Scotland (NHS QIS), Edinburgh. (As above)

Guidance on cancer services: improving supportive and palliative care for adults with cancer – Manual (2004) National Institute for Clinical Excellence (NICE), London; printed copies from NHS Response line 0870 1555 455; website: www.nice.org.uk/page.aspx?o=110005

Guidelines (various) Scottish Intercollegiate Guidelines Network (SIGN) 28 Thistle Street, Edinburgh EH2 1EN; tel 0131 718 5090; fax 0131 718 5114; website: www.sign.ac.uk

Nursing People with Cancer in Scotland: a Framework (2004), Scottish Executive, Edinburgh. Available from Blackwells Book Shop, 53/62 South Bridge, Edinburgh EH1 1YS; tel 0131 622 8283 fax 0131 622 8149; email: business.edinburgh@blackwells.co.uk

INTEGRATED CARE PATHWAYS

Integrated care pathways are a locally agreed, multidisciplinary document used for planning and documenting care for a particular patient/client group. Use of a pathway, whereby care details are recorded within specific time intervals, simplifies communication between health professionals and helps in evaluating care outcomes and so contributing to continuous improvement in the quality of care.

LIVERPOOL CARE PATHWAY

The Liverpool Care Pathway for the Dying Patient (LCP) is an example of an integrated care pathway (see above.) It is a single, comprehensive, record of care to be used in the last days of life. It replaces other forms of documentation and aims to ensure consistently high standards of care. Originally developed for use in hospital, it has now been adapted for use in different settings, including care homes. (See Hockley et al (2004) in Additional Reading above.)

The LCP provides guidance on the different aspects of care required at the end of life, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. It enhances communication and makes sure any symptoms that might be experienced in the last few days of life are anticipated and controlled. Psychological and spiritual care and family support are also highlighted.

For additional information see Ellershaw J & Wilkinson S (2003) in Additional Reading (above) and the Liverpool Care Pathway website *Providing best practice for care of the dying* at www.lcp-mariecurie.org.uk

MEDICINES

Useful sources of information on the administration and handling of medicines include:

Nursing & Midwifery Council (2004) *Guidelines for the Administration of Medicines* NMC, London website: www.nmc-uk.org/nmc/main/publications

Royal Pharmaceutical Society of Great Britain (2003) *The Administration and Control of Medicines in Care Homes and Children's Services* website: www.rpsgb.org

Royal Pharmaceutical Society of Great Britain (2005) *The Safe and Secure Handling of medicines: a Team Approach* (a revision of the Duthie report 1988) website: www.rpsgb.org

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (2001) *Position Statement on the Covert Administration of Medicines – Disguising Medicines in Food and Drink* London, UKCC Nursing & Midwifery Council, 23 Portland Place, London, W1B 1PZ, Tel: 020-76377181; website: www.nmc-uk.org/nmc/main/publications

NATIONAL CARE STANDARDS

National Care Standards were established under the Regulation Of Care (Scotland) Act 2001 (see below.) There are a number of different national care standards for different groups of people and different care settings. These palliative care practice statements are based on the national care standards for older people: *National Care Standards: Care Homes for Older People*, Edinburgh, Scottish Executive (available from: Blackwells Book

Shop, 53/62 South Bridge, Edinburgh EH1 1YS; tel: 0131 622 8283; fax: 0131 622 8149;
email: business.edinburgh@blackwells.co.uk

PAIN ASSESSMENT

Controlling painful symptoms is an important part of palliative care. However, it is not always easy to determine whether someone is in pain, particularly if they are unable to communicate clearly. A number of tools have been developed within palliative care to help with specific aspects of this problem:

- **Abbey Pain Scale**

The Abbey Pain Scale was developed in Australia for measurement of pain in people with dementia who cannot verbalise. It is a single page form that can be completed within one minute. It is also used in the UK, and is reproduced in *The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia*, Abbey J, Piller N et al, *International Journal of Palliative Nursing*, 2004, Vol 10, No 1, pp6-13.

- **Disability Distress Assessment Tool (DisDAT)**

This is a chart designed to help identify distress in people with learning disability. It is based on becoming aware of a person's normal method of communicating different things, which makes it easier to identify when something has changed and the person is distressed. Available from Dr Claud Regnard, St Oswald's Hospice, Regent Avenue, Gosforth, Newcastle Upon Tyne NE3 1EE; tel 0191 285 0063;
email: enquiries@stoswaldsuk.org

- **DOLOPLUS 2 Scale**

This is a pain assessment tool designed by geriatricians specifically for older people with advanced dementia. It has been extensively validated. The DOLOPLUS web-site (see below) has a good training package to teach you how to use the scale properly. (It appears in French: go to the foot of the screen and click on English.) Lefebvre-Chapiro S & the DOLOPLUS Group (2001) *The DOLOPLUS 2 Scale – evaluating pain in the elderly* *European Journal of Palliative Care* 8 (5) pp191-4;
website: www.doloplus.com

- **Palliative Care Outcome Scale (POS) and Support Team Assessment Schedule (STAS)**

These were developed as audit tools to measure the effect of palliative care. These have been found to be useful as summaries of a person's palliative care needs. They are made up of a set of statements and potential answers numbered 0-4.

POS has three different versions which are to be used depending on who fills out the scale, the patient, their family or a care professional. STAS was designed for the care professional to complete, but is more effective if the patient is involved in its completion. Permission is required to use STAS.

Palliative Care Outcome Scale (POS): Hearn J & Higginson IJ (1999) *Development and validation of a core outcome measure for palliative care: the palliative care outcome scale*, *Quality in Health Care* (8), pp219-27.

Support Team Assessment Schedule (STAS): Higginson IJ (1993) *A community schedule* in Higginson IJ (ed) *Clinical Audit in Palliative Care*, Oxford Radcliffe Medical Press, pp34-34.

- **SIGN 44**

This is a document which outlines best practice for management of pain in patients with cancer. It describes everything you should do when assessing a patients' pain and gives examples of pain assessment tools (documents which you can follow). Scottish Intercollegiate Guidelines Network & Scottish Cancer Therapy Network (2000) **SIGN 44: Control of Pain in Patients with Cancer**, Edinburgh, Scottish Intercollegiate Guidelines Network 7-9; website: www.sign.ac.uk

These are only a sample of the tools available for the assessment of pain. It is important to use pain assessment tools consistently if they are to be effective, and care home staff are advised to seek advice from others who use them such as their local specialist palliative care services, community psychiatric nurses, dementia care coordinators etc.

Other helpful sources of information on the management of pain include:

British Medical Association & Royal Pharmaceutical Society of Great Britain (2004) **British National Formulary** (BNF) 48, Pharmaceutical Society, London; website: www.BNF.org

NHS Quality Improvement Scotland (NHS QIS) **Best Practice Statements** eg **Best Practice Statement of Pain in Patients with Cancer** (April 2004) NHS QIS, Elliott House, 8-10 Hillside Crescent, Edinburgh EH7 5EA; tel: 0131 623 4300; email: comments@nhshealthquality.org website: www.nhshealthquality.org/nhsqis

Twycross R, Wilcock A, Charlesworth S & Dickman A (2002) 2nd edition **Palliative Care Formulary** PCF2 Abingdon, Radcliffe Medical Press.

For assessment of symptoms other than pain, see local / regional symptom control guidelines available on the websites of NHS Boards and Regional Cancer Networks.

PALLIATIVE CARE

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.

The World Health Organization (see also Additional reading above) first defined palliative care in the context of cancer care in the early 1990s but has recently updated the definition to include diseases other than cancer:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of pain and suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

(Sepulveda et al (2002) Journal of Pain and Symptom Management, 24 (2) 91-96) and

'Palliative care:

- **provides relief from pain and other distressing symptoms**
- **affirms life and regards dying as a normal process**
- **intends neither to hasten nor postpone death**

- *integrates the psychological and spiritual aspects of patient care*
- *offers a support system to help patients live as actively as possible until death*
- *offers a support system to help the family cope during the patients illness and in their own bereavement*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
- *will enhance quality of life, and may also positively influence the course of illness*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'*

(World Health Organization July 2002;

website: www5.who.int/cancer/main.cfm?p=0000000427)

Palliative care can be provided at any stage after diagnosis of a life-limiting illness or condition, but it has increasing importance 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

This is the basis of what is usually termed general palliative care (see below). It is a basic approach to caring for people as individuals, and recognises that they may have needs which are physical, social, psychological or spiritual, or a combination of these. Although particularly appropriate when dealing with long-term progressive conditions, a palliative care approach is in fact the underlying basis of all good care. It can and should be adopted by anyone in a caring role, whether paid carers, volunteers, family or friends.

These palliative care practice statements require that everyone working in a care home should be aware of this basic approach to care.

Palliative care principles

All palliative care is based on the understanding and practice of palliative care principles. These include:

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

General palliative care

General palliative care is based on the principles above and is provided for those who need it as part of normal care 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

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

Specialist palliative care services

There are a wide-ranging variety of specialist palliative care services across Scotland. These include:

- bereavement services
- day-care services
- home-care services (where care staff trained in palliative care (eg some Macmillan nurses) visit people in the community to give advice about palliative care needs)
- hospice-at-home (where care staff (eg Marie Curie nurses) trained in palliative care visit people in the community in order to provide palliative care
- information services
- inpatient palliative care services.

All of these services exist to provide and promote high quality palliative care. They are often anxious to support the palliative care approach in care homes by offering practical help in the form of staff support and equipment and/or advice. Finding out what specialist services are available in your area and becoming aware of what they can offer to support your care home will help to make your home's palliative care of the highest quality it can be.

Information about the location of specialist palliative care services in Scotland can be found:

- on the website of the Scottish Partnership for Palliative Care at www.palliativecarescotland.org.uk or
- in *Hospice Information (2006) Hospice and Palliative Care Directory, United Kingdom and Ireland 2006*, Help the Hospices, Hospice House, 34-44 Britannia Street, London, WC1X 9JG; tel: 0870-903 3903; website: www.hospiceinformation.info

PHARMACY

One of the factors crucial to effective palliative care is having appropriate medicines available and accessible for people who need them at all times of the day and night. Much thought has been given to finding the best ways of making this possible.

The Scottish Executive has published a *Toolkit for assessing the pharmaceutical needs of populations: Palliative care pharmaceutical services* (2004) to support practitioners and healthcare planners in undertaking health needs assessments and planning services for their local populations. The toolkit covers pharmacy/medicine issues and includes a useful reference list. It can be downloaded from the following website: www.ssipph.scot.nhs.uk/public_health_scotland/priority%20topics/PC%20toolkit.pdf

Community Pharmacy Pharmaceutical Care Model Scheme for Palliative Care

This Model Scheme was established to encourage community pharmacists to develop their services in ways which would better meet the palliative care needs of patients. The purpose of the scheme was to set-up networks of specialist community pharmacies which would maintain an agreed stock of palliative care medicines that could be accessed by people who required them. The pharmacists involved in the scheme have undergone additional training to enable them to provide specialist pharmaceutical advice to patients, carers, GPs, nurses and other community pharmacists. How the scheme works in each health board area varies.

Your local pharmacist should be aware of how the network scheme is operating in your area. If they cannot give you this information, you could contact local hospital or hospice pharmacists for advice. (See Scottish Executive (1999) MEL (1999) 78: *Community Pharmacy: Model Schemes for Pharmaceutical Care*, Scottish Executive Health Department.) Details of specialist palliative care pharmacists can be found on the website of the Scottish Partnership for Palliative Care on www.palliativecarescotland.org.uk

Out-of-Hours Pharmacy

The Clinical Standards for Specialist Palliative Care (see Additional Reading above) state that a list of essential drugs for palliative care should be agreed in each health board area and that these drugs should be available at all times. Care home staff should liaise with GPs and should be familiar with how to access these drugs when required. These arrangements may be easier where general practices are using the Gold Standards Framework (see above) and/or arrangements have been made for anticipatory prescribing (anticipating someone's palliative care needs by prescribing in advance any medicines they are likely to need at nights and weekends).

REGULATION OF CARE (SCOTLAND) ACT 2001

The Act established a new system of care regulation covering the registration and inspection of care services against a set of national care standards (see above). The Act also created two new national, independent bodies:

- the Scottish Commission for the Regulation of Care (known as the Care Commission) to regulate care services, and
- the Scottish Social Services Council to regulate the social service workforce and to promote and regulate its education and training.

SPECIAL NOTES

This is a brief note of the clinical details concerning a patient with palliative care needs which is forwarded to the Out-of-Hours Service to ensure that, should there be a call concerning the patient out-of-hours, it is dealt with quickly and appropriately.

SPIRITUAL CARE

Spirituality may be defined as whatever gives a person meaning, value and worth in his or her life. This includes religious and faith beliefs and practices (see Culture and beliefs above) as well as other aspects of life which are important to an individual. Caring for someone's spiritual needs is a vital part of the palliative care approach.

Marie Curie Cancer Care has developed a set of *Spiritual and Religious Care Competencies* which provide guidance on how spiritual care can be given. The competencies are set at four levels and identify which practitioners should achieve which levels. The competencies are supported by the Association of Hospice and Palliative Care Chaplains and can be downloaded from the following website:

www.mariecurie.org.uk/healthcare

Appendix 3: acknowledgements

These practice statements were developed at the request of the Scottish Executive by an expert working group set up by the Scottish Partnership for Palliative Care. The Partnership would like to thank all those who contributed to the final document, particularly members of the working group, the editorial team, and all those who responded to the consultation process.

Working group membership (2003-2004)

Susan Munroe (Chair)*	Caring Services Manager Scotland, Marie Curie Cancer Care and Deputy Chair of the Scottish Partnership for Palliative Care
Sylvia Cox	Planning Consultant, The Dementia Services Development Centre, University of Stirling
Dr Rosalie Dunn	Macmillan GP Facilitator, Udston Hospital, Lanarkshire
Dawn Foxley	Service Manager, Fife Palliative Care Service
Donna Gilmour*	Care Commission Officer, Care Commission
Hazel Hill*	Project Facilitator, Strathcarron Hospice, Denny, Stirlingshire
Jo Hockley	Research Fellow/Clinical Nurse Specialist, St Columba's Hospice, Edinburgh
Kitty Mason*	Planning & Commissioning Officer, Health and Social Care Department, City of Edinburgh Council
Elaine MacLean	Professional Adviser for Palliative Care, Care Commission
Donna MacLeod	Training and Development Manager, Kler Care Homes HQ, Tranent
Jane McGowan	Matron, Lizdean Nursing Home, Ayrshire
Isobel Pennie	Hospice As a Resource for Palliative Care Services (HARPS) Coordinator, Marie Curie Hospice Glasgow

* Members of editorial team (2004-2006)

Published by:
Scottish Partnership for Palliative Care
1a Cambridge Street
Edinburgh EH1 2DY

Tel: 0131 229 0538
Fax 0131 228 2967

office@palliativecarescotland.org.uk
www.palliativecarescotland.org.uk

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