

nationalcarestandards
hospice care

revised september 2005

dignity —

privacy —

choice —

safety —

realising potential —

equality and diversity —



SCOTTISH EXECUTIVE



national **care** standards
hospice care

dignity

privacy

choice

safety

realising potential

equality and diversity

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Introduction

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Introduction

Voluntary hospices in Scotland

In Scotland, hospices are part of the independent healthcare sector and are subject to regulation by the Scottish Commission for the Regulation of Care ('the Care Commission'). The hospices have charitable status and make no charge to the users of their services. They all receive part of their running costs from the NHS and all work in close partnership with local NHS services.

The national care standards for hospice care apply to **all** hospices. They include a small number of **additional** standards which are specific to the children's hospices only, and these are indicated in italics in the text. The children's standards are addressed to the child's parents or guardians.

Palliative care

Hospices provide palliative care for people with chronic, progressive conditions, including cancer. Palliative care aims to maintain and, as far as possible, improve the quality of life for people faced with a progressive illness such as cancer. Palliative care is concerned with:

- controlling pain and other distressing symptoms;
- helping patients and families cope with the emotional upset and practical problems of the situation;
- helping you to deal with spiritual matters which may arise from your illness;
- helping you to live as actively as possible despite your illness; and
- supporting families and friends throughout your illness and in their bereavement.

Hospice services

Most hospices provide a mix of in-patient care, day care and home care, although they do not all provide all three types of service. Patients are referred to the hospice by their GP or hospital doctor for whichever sort of care is best suited to their needs at the time. Some people might receive home care, day care and in-patient care over the course of their illness. Others might receive only a short period of hospice care to manage their symptoms or help with other problems arising from their illness. Hospices today are not just places where people go to die. A significant proportion of people admitted to a hospice are able to go home after a short stay.

Hospice care is provided by a multi-professional team who have undergone specialist palliative care training. Hospices which have a full team of appropriately qualified doctors, nurses and other healthcare professionals are recognised as providing specialist palliative care for those patients and families with complex needs.

The national care standards

Scottish Ministers set up the National Care Standards Committee (NCSC) to develop national standards. The NCSC carried out this work with the help of a number of working groups. These groups included people who use the services, their families and carers, along with staff, professional associations, regulators from health and social care, local authorities and independent health providers. Many others were involved in the consultation process.

As a result, the standards have been developed from the point of view of the person who uses the service. They describe what each individual person can expect from the service provider. They focus on the quality of life that the person using the service actually experiences and they apply to people using all aspects of hospice's services (in-patient care, day care, home care and out-patient care) unless the standard is inappropriate for the aspect.

Links to NHS Quality Improvement Scotland¹

The Care Commission is responsible for regulating the independent healthcare sector (including hospice services) taking account of the national care standards developed and issued by Scottish Ministers for this sector.

NHS Quality Improvement Scotland (NHS QIS) sets standards and monitors performance in the NHS to improve the quality of healthcare in Scotland.

People using services should be able to expect that standards set by NHS QIS will apply, where appropriate, in both the NHS and independent healthcare sectors. These standards include a standard (5.6) to help make sure this happens in hospice services.

The Care Commission, in making sure these shared standards are met by hospice services, will liaise with NHS QIS. A written agreement (or 'memorandum of understanding') will cover the working relationship between the Care Commission and NHS QIS.'

Using the national care standards

If you are thinking about using the services of a hospice, you may want to refer to the standards to help you decide. If you are already using the service, you may use the standards when discussing the service you receive with the staff and managers of the service, people involved in referring you to the service or someone acting on your behalf.

Standards make it clear that everything about the service is focused on the quality of life you experience as a result of receiving the service. If things go wrong, you can refer to the standards to help you raise concerns or make a complaint. (See 'Expressing your views', standard 21.)

¹ On 1 January 2003, NHS Quality Improvement Scotland took over the functions previously carried out by the Clinical Standards Board for Scotland.

The principles behind the standards

The standards are based on a set of principles. The principles themselves are not standards but reflect the recognised rights which you enjoy as a citizen. These principles are the result of all the contributions made by the NCSC, its working groups and everyone else who responded to the consultations on the standards as they were being written. They recognise that services must be accessible and suitable for everyone who needs them, including people from black and ethnic minority communities. They reflect the strong agreement that your experience of receiving services is very important and should be positive, and that you have rights.

The main principles

The principles are dignity, privacy, choice, safety, realising potential and equality and diversity.

Dignity

Your right to:

- be treated with dignity and respect at all times; and
- enjoy a full range of social relationships.

Privacy

Your right to:

- have your privacy and property respected, and to receive the time, the space and the facilities you need and want; and
- be free from intrusion as long as it is safe for you and everyone else.

Choice

Your right to:

- make informed choices, while recognising the rights of other people to do the same;
- know about the range of choices; and
- get help to fully understand all the options and choose the one that is right for you.

Safety

Your right to:

- feel safe and secure in all aspects of life, including health and wellbeing;
- enjoy safety but not be over-protected; and
- be free from exploitation and abuse.

Realising potential

Your right to have the opportunity to:

- achieve all you can;
- make full use of the resources that are available to you; and
- make the most of your life.

Equality and diversity

Your right to:

- live an independent life, rich in purpose, meaning and personal fulfilment;
- be valued for your ethnic background, language, culture, and faith;
- be treated equally and live in an environment which is free from bullying, harassment and discrimination; and
- be able to complain effectively without fear of victimisation.

The Scottish Commission for the Regulation of Care

The Regulation of Care (Scotland) Act 2001 ('the Act') set up the Care Commission, which registers and inspects all the services regulated under the Act, taking account of the national care standards issued by Scottish Ministers. The Care Commission has its headquarters in Dundee, with regional offices across the country. It will assess applications from people who want to provide hospice care. It will inspect the services to make sure that they are meeting the regulations and, in doing so, will take account of the national care standards. You can find out more about the Care Commission and what it does from its website (www.carecommission.com).

The Scottish Social Services Council

The Act created the Scottish Social Services Council ('the Council') which was established on 1 October 2001. It also has its headquarters in Dundee. The Council has the duty of promoting high standards of conduct and practice among social services workers, and in their education and training. To deliver its overall aims of protecting service users and carers and securing the confidence of the public in social services, the Council has been given five main tasks. These are: to establish registers of key groups of social services staff; to publish codes of practice for all social services staff and their employers; to regulate the conduct of registered workers; to regulate the training and education of the workforce; to undertake the functions of the National Training Organisation for the Personal Social Services. The Council has issued codes of practice for social service workers and employers of social service workers. These describe the standards of conduct and practice within which they should work. The codes are available from the Council website (www.sssc.uk.com).

How standards and regulations work together

The Act gives Scottish Ministers the power to publish standards which the Care Commission must take into account when making its decisions. It also gives Scottish Ministers the power to make regulations imposing requirements in relation to hospice care services.

The standards will be taken into account by the Care Commission in making any decision about applications for registration (including varying or removing a condition that may have been imposed on the registration of the service). All providers must provide a statement of function and purpose when they are applying to register their service. On the basis of that statement, the Care Commission will determine which standards will apply to the service that the provider is offering.

The standards will be used to monitor the quality of services and their compliance with the Act and the regulations. If, at inspection, or at other times, for example, as a result of the Care Commission looking into a complaint, there are concerns about the service, the Care Commission will take the standards into account in any decision on whether to take enforcement action and what action to take.

If the standards were not being fully met, the Care Commission would note this in the inspection report and require the service manager to address this. The Care Commission could impose an additional condition on the service's registration if the provider persistently, substantially or seriously failed to meet the standards or breached a regulation. If the provider does not then meet the condition, the Care Commission could issue an improvement notice detailing the required improvement to be made and the timescale for this. Alternatively, the Care Commission could move straight to an improvement notice. The Care Commission would move to cancel the registration of any service if the improvement notice does not achieve the desired result. In extreme cases (i.e. where there is serious risk to a person's life, health or wellbeing) the Care Commission could take immediate steps to cancel the registration of any service without issuing an improvement notice.

Regulations are mandatory. In some cases not meeting a regulation will be an offence. This means a provider may be subject to prosecution. Not meeting or breaching any regulation is a serious matter.

Decisions by the Care Commission on what to do when standards or regulations are not met will take into account all the relevant circumstances and be proportionate.

You can get information on these regulations from the *Regulation of Care (Scotland) Act 2001*, which is available from the Stationery Office Bookshop. You can also see the Act on-line (see Annex B for the address).

You can also see the Scottish Statutory Instruments for the Regulation of Care Regulations 2002 on-line (see Annex B for the address).

Comments

If you would like to comment on these standards you can visit our website and send a message through our mailbox:

www.scotland.gov.uk/health/standardsandsponsorship

You can also contact us at:

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1-4

Before using the service

- 1 Informing and deciding
- 2 Assessing your needs
- 3 Guidelines and legal matters
- 4 Premises

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Informing and deciding

Standard 1

You can make a positive and informed decision about using the hospice services, helped by the quality and accuracy of the information you receive.

- 1 You know that local hospitals and GPs receive information from the hospice about its services and its criteria for referral, so that they can help you to come to a decision about the services.
- 2 You receive clear and accurate information in plain English or in a language or format that you can easily understand. The information includes:
 - details of the aims and philosophy of the hospice;
 - criteria for admission to hospice in-patient, home care and day care services;
 - details of the services provided by the hospice;
 - contact names and telephone numbers;
 - details of the hospice comments, suggestions and complaints policy;
 - practical arrangements for admission, transport and visiting; and
 - your responsibilities towards the hospice.
- 3 You have the opportunity, if you are well enough and want to do so, to visit the hospice in advance. If you want, family members or carers may visit in advance, too, either with you or on your behalf.
- 4 You have access to the hospice policy on statements regarding your views on future treatment (for example, a living will or advance statement) and on resuscitation.
- 5 You have access to the hospice services based on your identified needs and as far as possible your individual preferences.

- 6 Your access to hospice services is not compromised by any physical, language, cultural or other barriers. If your first language is not English or if you have any other communication needs, you have help to use interpreting services, adaptations and equipment for communication.

Assessing your needs

Standard 2

You receive services that respond to your needs and preferences. You are involved in decisions about your own care, through effective two-way communication and sharing of information.

- 1 You take part in an initial assessment made by the most appropriate member of the multi-professional team to help determine what care you need and prefer.
- 2 You receive information and have an opportunity to discuss the care proposed for you, what results are expected and your expected length of stay. With your consent, members of your family, or your carers, will also receive the information.
- 3 You know that there is a full multi-professional assessment of your physical, social, psychological, spiritual and intellectual needs.
- 4 Before your plan of care is agreed, staff explain your condition clearly to you in as much detail as you want. They also explain any treatment, investigation or procedure proposed, including the risks and alternatives, so that you have the information necessary to give your informed consent.
- 5 If, at any time, you are unable to express your wishes or views, including giving your consent, about your care or treatment, you know that hospice staff will make any decision in line with legislation² and best-practice guidance.
- 6 You are involved in making decisions about your care. With your consent, your family or carers are also involved in decisions, as appropriate.

² Adults with Incapacity Act 2000; Mental Health (Scotland) Act 1984; General Medical Council, *Seeking Patients' Consent: The Ethical Considerations*.

- 7 You know that the hospice keeps an accurate, up-to-date record on all aspects of your care which is readily available to any clinician involved in your care.
- 8 You know that the hospice communicates information on your care to the other clinicians involved in delivering that care.
- 9 *You know that staff are aware of the law³ on whether children are able to agree to receive, and understand the consequences of, medical treatment.*

³ Age of Legal Capacity (Scotland) Act 1991; Children (Scotland) Act 1995 – Section 6 Part 1.

Guidelines and legislation

Standard 3

You can be confident that your legal and human rights will be protected and that the service is managed in line with all applicable legal requirements.

- 1 You know that all aspects of your care are delivered within the law and according to best-practice guidelines, where they exist.
- 2 Your safety is maintained by the hospice having risk assessment management systems in place. These take account of all relevant legislation and current best practice, including CNORIS Standards.⁴
- 3 You know that the hospice has up-to-date documentation regarding its policies and procedures for all relevant legislation and best-practice guidelines. These include:
 - fire, including evacuation procedures;
 - security, including the protection of vulnerable adults;
 - environmental health, including food safety; and
 - security of belongings and valuables that you bring into the hospice.
- 4 You know that any accident or incident that happens will be reported by staff and volunteers and that it will be investigated.
- 5 Your human rights and privacy are preserved and any information you give to any staff and volunteers of the hospice remains confidential unless there is a lawful basis for disclosure of information.
- 6 You have access to your own records in line with legislation. The records are kept confidentially and securely.

⁴ Clinical Negligence and Other Risks Indemnity Scheme (CNORIS) Healthcare Risk Management Standards.

- 7 You are informed about what statistical information, including information that identifies you as the patient, may be collected about your condition and treatment and what it will be used for. Your consent is sought to the collection of such information.
- 8 You know that staff work in line with the provisions of any mental health legislation which affects your rights and care.

Premises

Standard 4

You feel safe and comfortable in the hospice and can be confident that your right to privacy is protected.

- 1 You are cared for in an environment that is safe, comfortable, allows your care to be delivered effectively and safely and protects your right to privacy and confidentiality.
- 2 The hospice is accessible to you and those important to you. This includes:
 - being accessible in a wheelchair;
 - having suitable car parking;
 - being easy to find your way around; and
 - being accessible by public transport (this applies to new hospices only).
- 3 You, and those important to you, can easily get help from members of staff by using the nurse call system.
- 4 You, and those important to you, can easily contact the hospice and the staff members by a telecommunications system appropriate to the size of the hospice.
- 5 Your environment is suitable for the social, psychological and spiritual care you need. This will include:
 - all rooms that you use will be well maintained and there will be good use of lighting, decor and furnishings;
 - where your health and the needs of other patients permit, you will have the choice of whether you are cared for in a single room or a shared room;
 - there will be an area where you and your visitors can be welcomed to the hospice and can wait in comfort for an appointment if necessary;
 - you will have the key to a lockable storage space in your room; and

- an area or accommodation where your relations and others important to you can stay overnight and an area where your friends and family can visit you in privacy.
- 6 Your environment is suitable for the care you require. There will be:
- accommodation for the range of care and treatment that is delivered by the hospice. This includes:
 - necessary medical procedures;
 - physiotherapy;
 - occupational therapy;
 - out-patient consultations; and
 - day care.
 - adequate smoking and non-smoking lounges;
 - enough electric sockets to support all equipment required;
 - an oxygen supply;
 - arrangements in place to ensure an uninterrupted electrical supply;
 - toilets you can use, or be assisted to use, easily and that you can get to easily from all patient areas;
 - a range of baths and showers to allow you to bath or shower independently if you want and are able, or to be assisted to bath or shower if and when needed; and
 - bed spaces and single rooms of an adequate size to house all equipment required for your care.
- 7 You can vary the heating, lighting and ventilation in your room.

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Having confidence in your care

- 5 Quality of care and treatment
- 6 Staff
- 7 Infection control
- 8 Medicines
- 9 Equipment
- 10 Care of children

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Quality of care and treatment

Standard 5

You receive high quality, safe, supportive and effective care and treatment based on available up-to-date evidence.

- 1 You are told the names and job titles of the key healthcare professionals responsible for managing your care and how to contact them.
- 2 You know that there is a process for measuring and reviewing the performance of clinical treatment and care against best-practice guidelines.
- 3 You know that the process of review will lead to changes in practice and improvements in the standards of care you receive.
- 4 You know that all healthcare staff take part in the process of review and the development of improvements to practice and can request information about this.
- 5 You know that the safety of work practice and the working environment is ensured by a process of risk management.
- 6 You know that the care and treatment you receive from the hospice takes account of all relevant NHS Quality Improvement Scotland standards.⁵

⁵ See 'Links to NHS QIS' paragraph on page 6.

Staff

Standard 6

You can be confident that your care will be provided by a multi-professional team of staff and volunteers who are suitably qualified and/or skilled for the job.

- 1 You know that the staff caring for you have the appropriate qualifications, experience and competencies for the job they are required to undertake and are given the necessary resources to do their job.
- 2 You know that all recruitment and selection to the hospice follows a clearly written recruitment and selection policy. The hospice checks the qualifications and current registration status of all staff and (where appropriate) volunteers and all necessary records, including criminal records checks, before they start work and, if necessary, on a regular basis.
- 3 You know that there is regular performance management and that every member of staff has a personal professional development plan which reflects the recommendations of professional and regulatory bodies.
- 4 You know that the hospice:
 - has an education and training strategy, including induction training, which meets the needs of staff and volunteers and the services they provide;
 - identifies and meets staff and volunteers' training needs;
 - promotes effective teamwork across all disciplines and with staff in other organisations, including NHS hospital and community services and local authority social work services; and
 - has adequate space for multi-professional staff meetings.
- 5 You know that all professional staff demonstrate responsibility and accountability for their own professional practice.

- 6 You know that the hospice:
- supports staff in dealing with stress at work; and
 - enables staff to have access to occupational health, including counselling support, on a confidential basis, as and when required.
- 7 You know that the hospice:
- has a whistle-blowing policy and procedure to help staff and volunteers raise concerns in confidence over any aspect of service delivery they feel may be harming your care and the care of others, or the quality of service; and
 - keeps a confidential record of all staff and volunteers' concerns and of the action taken in response.
- 8 *Where sick children are cared for, you know that a minimum of one Registered Sick Children's Nurse (RSCN) will be on duty at all times. Adequate RSCNs will be deployed to reflect the nursing needs of the children staying in the hospice.*
- 9 *You know that a child protection awareness and procedures are part of the mandatory training for staff looking after children and that the training takes place at least once a year.*

Infection control

Standard 7

You are protected from contracting preventable infections while in the hospice. If you are admitted with an infection, you receive appropriate care.

- 1** You are cared for by staff who are trained and competent in minimising the risk of cross-infection and follow an infection control policy, which is reviewed annually.
- 2** You know that staff and volunteers are educated about the infection control policy, taking account of their grade, role and responsibility.
- 3** You know that staff take appropriate steps to avoid you acquiring preventable infection.
- 4** You know that staff always make sure that their hands are cleansed thoroughly before and after treating you.
- 5** You are fully involved and informed so that you can understand the need for infection control procedures and policies.
- 6** If you have an infection, the hospice will take appropriate steps to protect other patients and staff from acquiring your infection.
- 7** You are treated with dignity by staff if you have an infection. They take account of your wishes in planning the most appropriate care for you as an individual.

Medicines

Standard 8

Medication forms a significant part of controlling your symptoms. The hospice will manage your medication to maximise the benefit and minimise the harm.

- 1 You have the correct medicines, prescribed and administered safely, in time and in good condition. This means that:
 - any medicines you bring into the hospice are recorded and stored safely and used, if necessary, only for your treatment;
 - prescribed medicines are available at all times;
 - all medicines are stored securely and in appropriate conditions;
 - all equipment for medicines administration is well maintained and used safely and in line with current guidelines;
 - you can make informed choices about your medication;
 - any specialist treatment is provided by staff with specialist training; and
 - any medicines you bring into the hospice and do not require at discharge will be safely disposed of. Disposal will be in line with legal requirements.

- 2 When you are discharged from the hospice, you will be able to continue to take your medicines safely. This means that:
 - you are given an appropriate supply of your current medicines at the time of discharge – this will normally be a seven-day supply;
 - you will have been given a written and verbal explanation of the medicines you are to take and what they are for; this information can be given to a member of your family or carer if you prefer or if staff feel that it is necessary;
 - you, or your carer, will be familiar with any equipment you will need to take your prescribed medicines;

- you will have in place any equipment you need to take the prescribed medicines, and you and your carer will have been shown how to use it and informed how to seek help when needed;
 - procedures will be in place to make sure that you can obtain any specialist medicines you need;
 - any special needs relating to the dispensing of your medicines are formally assessed and clearly documented, and staff will address these needs;
 - you will be prescribed and supplied with medicines in a form that is safe and easy for you to take; and
 - any special needs relating to the dispensing of your medicines have been agreed with your local pharmacy.
- 3** When you attend day care:
- you are responsible for your own medicines, but if you need help to take them this will be available;
 - procedures are in place to make sure that if you do need to take medicines, which you do not have with you, these will be safely and legally administered; and
 - any changes to your medicines recommended by a member of the hospice team will be communicated to your doctor (GP) quickly to allow a decision to be made and a prescription to be issued, if necessary.
- 4** When you receive home care, the home care team will review your medicines and make sure that you can continue to take these easily and safely. If changes are needed, these will be discussed with your own doctor (GP).
- 5** If you are capable of giving your consent to being treated with medication and then refuse it and understand the consequences of refusal, staff must respect this.

- 6 You may not understand that you need to take medication and what will happen if you do not do so. If so, there are legal powers⁶ that allow other people to give permission for you to receive treatment if it is necessary for your health and welfare. Staff will not give medication except in accordance with the law. Even where the law allows medication to be given without consent, it will not be given in a disguised form unless you have refused and your health is at risk because of this. This will be recorded.

⁶ UKCC Position statement on the covert administration of medicines 2001; Adults with Incapacity Act 2000; Mental Health (Scotland) Act 1984.

Equipment for therapeutic and monitoring purposes

Standard 9

You can be confident that any equipment⁷ needed to support your care will be available. There will be appropriate provision, maintenance, repair and use of equipment suitable for patients with palliative care needs.

- 1** Your equipment needs are assessed as an ongoing and integral part of your care.
- 2** You have the equipment needed for your care in the hospice available for use by you, staff and those important to you, when appropriate.
- 3** You know that staff are aware of the equipment available to you and use to assist with your care and rehabilitation.
- 4** You know that all staff using and prescribing equipment for your care have the appropriate training.
- 5** You know that all equipment used in your care is part of a planned maintenance programme, and that all equipment is used safely and in line with the manufacturer's instructions.
- 6** You know that any equipment needed for your discharge will be identified and arranged as early as possible in your care. Wherever possible, it will be in place before your discharge.

⁷ In the following standards the word 'equipment' is used for all rehabilitation, monitoring and treatment devices.

Care of children

Standard 10

You can be confident that the rights of sick children will be respected and protected.

- 1 You know that staff and volunteers will demonstrate sensitive methods of care and management in their day-to-day contact with children.*
- 2 You have information available appropriate to children's needs and stage of development.*
- 3 You know that children's rights are promoted by staff and volunteers, who are sensitive to any signs which may indicate possible neglect or abuse. Staff will make sure that any concerns are quickly dealt with.*

11-19

Getting the most out of life

- 11 Living with illness
- 12 Wellbeing
- 13 Personal life
- 14 Daily life
- 15 *Play, education and leisure*
- 16 Keeping in touch
- 17 Enjoying food
- 18 Caring for those important to you
- 19 *Support and care for you as a family*

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Living with illness

Standard 11

You receive support from the hospice in your illness and are helped to continue to get the most out of life.

- 1 You receive encouragement, help and support to enable you to achieve your full potential, maintain your independence for as long as possible, and adapt to your changing condition.
- 2 You have the opportunity to discuss realistic aims for your care. These aims are reviewed regularly and reflect any changes in your condition.
- 3 Your plan of care focuses on rehabilitation in order to maximise your quality of life within any limits imposed by illness.
- 4 You are made aware of any financial, social and legal supports available to you. If needed, you are helped to use them.
- 5 You have multi-professional support to enable you to live as actively as you are able.

Wellbeing

Standard 12

You feel respected as an individual and all your needs are recognised.

- 1 You are treated with respect and are supported and assisted as you explore physical, psychological, social, spiritual and intellectual areas of need.
- 2 You are respected as a person, for your ethnicity, gender, sexual orientation, faith, age, intellect, disability.
- 3 You are helped to identify the problems that concern you most.
- 4 You have your physical symptoms actively managed according to best current practice, while being made aware of any treatments or services which may help you to cope better.
- 5 You can spend time with staff and volunteers, exploring any issues of concern to you.
- 6 You are supported by staff as you try to adjust to your condition and try to find some sense of meaning in your experience.
- 7 You can continue to follow your religious and spiritual practices as fully as possible.

Personal life

Standard 13

You are supported to achieve the right balance for you between privacy and companionship.

- 1 You can have periods of solitude if that is your choice, while also sharing time with those who are important to you.
- 2 You have the reassurance of companionship when that is important to you.
- 3 You are enabled to continue to feel part of your family group.
- 4 You can receive visitors in privacy.
- 5 You are enabled to continue with hobbies and interests, whenever possible.

Daily life

Standard 14

You feel comfortable and at ease in your care environment, with the pattern of your daily care routine reflecting your chosen lifestyle.

- 1** You have your choices reflected in your care routine.
- 2** You have the opportunity to discuss your needs, along with those of your family and carers, and others within your care environment.

Play, education and leisure

Standard 15

You can be confident that play, education and leisure are recognised as being a vital part of children's daily lives.

- 1** *You know that staff and volunteers have a range of communication skills appropriate for children of all ages and ability.*
- 2** *You know that children's play, educational and leisure needs are assessed, in order to maximise independence, ability and enjoyment. This forms an integral part of the plan of care.*
- 3** *You know that the hospice provides an educationally-rich environment, with study facilities. Staff will help children to manage study time effectively and they will work with children's nurseries, schools or colleges (if appropriate) to aid communication and provide continuity.*
- 4** *You know that children have a range of appropriate toys, games and play equipment available in their own room or in a separate play area.*
- 5** *You know that brothers and sisters are actively involved in play, and staff and volunteers are sensitive to their needs.*

Keeping in touch

Standard 16

You receive support to stay involved with the people and organisations which are important to you.

- 1 You continue to be in touch with the people who are important to you.
- 2 You enjoy a system of open visiting when your energy and inclination allow.
- 3 You have a telephone available for your use in a private area.
- 4 You are enabled to have visits out when possible.

Enjoying food

Standard 17

You are supported to enjoy your food, and are offered a choice and variety which respects your ethnic, cultural and dietary requirements.

- 1 You know that the hospice complies with all current environmental health and food safety legislation.
- 2 You are consulted regarding your preferences and choice of food, including any ethnic, cultural, faith or other preferences you have.
- 3 Your nutritional needs are assessed, including any special dietary needs. With your agreement, staff will take any action needed, such as seeking advice from a dietitian.
- 4 You have menus that are planned to offer a balanced choice for each meal.
- 5 You have a choice of snacks, drinks and food available when you wish.
- 6 If you are unable to eat or drink normally, staff are able to carry out any special method of feeding that you may need.
- 7 You know that staff are sensitive to any practical help you may need to enjoy your food and drink (for example, liquidised and thickened meals).

Caring for those important to you

Standard 18

You know that the hospice will support your family and carers.

- 1** You know that the needs of those important to you will be identified and met in a sensitive manner. Your family, friends and carers will be supported by a multi-professional team, if they wish.
- 2** You know that those involved in caring for you will be given information and support to assist them if desired, while respecting your confidentiality. Your consent is needed if information about your condition is to be shared with others. This is to ensure your privacy, and your wishes will be respected.
- 3** You know that staff and volunteers will communicate appropriately and sensitively with visiting children, allowing them to express themselves and providing opportunities for play.

Support and care for you as a family

Standard 19

You know that a children's hospice recognises the special needs of yourselves and the well children in the family.

- 1** *You have accommodation available to you free of charge, enabling you to stay together as a family.*
- 2** *You can take part as much or as little as you want in your child's daily care.*
- 3** *You are central in any decision-making processes affecting your child and family.*
- 4** *You have care and support from a multi-disciplinary team to help you to adjust to, and live with, changes that you may be experiencing in your life.*
- 5** *You have the opportunity to discuss how best to meet the needs of the well children in your family*
- 6** *You can use the free complementary therapies provided by the hospice, if you want.*

20

Moving on

20 Planning your discharge

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Planning your discharge

Standard 20

Your discharge from the hospice will be a smooth transition to ongoing care. The hospice has comprehensive procedures for planning your discharge in partnership with yourself and others involved.

- 1 Your plan of care includes planning in advance for your discharge. Planning begins as soon as a decision is made about your ongoing care needs.
- 2 You are fully involved in planning your discharge, in partnership with staff, your family and carers. Your GP, community nurses and social work services are encouraged to be involved in the planning.
- 3 You have all relevant information communicated in good time to you and to any others involved in your ongoing care.
- 4 You are discharged only when follow-up services (including equipment and adaptations where required) have been arranged, unless you choose otherwise. Staff will record reasons for any delay in your discharge.
- 5 You receive information on discharge about plans for your ongoing care, including your medication.

21

Expressing your views

21 Advocacy, concerns, comments and complaints

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Advocacy, comments, concerns and complaints

Standard 21

You can be confident that the hospice will welcome your views on services, so that it can continuously improve the quality of its care. If you feel unable to voice your views, you will receive support from a representative of your choice.

- 1 You, and those important to you, are encouraged to express any views you may have on any aspect of the hospice service, either personally or through your chosen representative.
- 2 You are supported in a safe and confidential manner to make known any views, whether positive or negative, on any aspect of your care.
- 3 If you wish to have other people to help you express your views, staff will have information they can give you about any independent and confidential service that would help you in this way. Staff will support you to use it.
- 4 You or your representative have access to easily understood internal and external complaint procedures. They include information about who to make complaints to and how to contact the Care Commission.
- 5 You have access to the latest report on the hospice by the Care Commission, if you want to see it.
- 6 Your concerns or complaints are dealt with promptly and sympathetically, and full information is provided to you about what happens as a result.
- 7 You know that staff will listen to your chosen representative as if the views expressed were your own and will respect any outcomes in the same way.
- 8 You can be confident that any concerns you have about your clinical treatment will be properly dealt with by the appropriate organisation.

22

Care at the end of life

22 Around the time of death

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Around the time of death

Standard 22

If you are approaching death, you, and those important to you, are helped to come to terms with it and to express your preferences for your care.

- 1 Your wishes are sought, discussed with you and taken into consideration when planning the care you receive in the last few days and hours of your life and how your body is treated after your death.
- 2 When it is appropriate, your preferred place of death is discussed with you and those important to you and every effort is made to carry out your wishes.
- 3 You are able to choose whether or not you wish to have someone with you when you die and who that person should be. Every effort is made to achieve this.
- 4 Those important to you have facilities available to stay with you during your last few days and hours, if that is your and their wish.
- 5 When you die, your body is treated with dignity, sensitivity and respect and in accordance with your expressed religious, faith or cultural preferences.
- 6 Those important to you have suitable facilities to spend as much time with you after your death as they require.
- 7 Those important to you are offered continued support during your last hours and are offered the support of a bereavement service after your death.
- 8 *Staff are sensitive to your needs and wishes during the later stages of your child's life.*
- 9 *You and your child's wishes are identified as to the preferred place of death – home or hospice.*

- 10 *You know that a children's hospice provides a special room for your child's body to be laid in during the time between death and the funeral, if you want to use it. This facility is available to you wherever your child dies.*
- 11 *Your family is invited to stay at the hospice during this time.*
- 12 *After your child's death, a bereavement support service is available to you, based on your individual identified needs.*

Annex A

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Annex A

Glossary

Living will

Also called 'advance directive' or 'advance statement'. A statement made when a person is competent (has capacity), detailing how they wish to be treated if, in time, they become unable to express this for any reason. These statements are not legally binding but are taken into account by all members of the healthcare team.

Medication

A substance administered for treatment purposes.

Occupational therapy

Occupational therapy is the treatment of people with physical and psychiatric illness or disability through specific selected occupation for the purpose of enabling individuals to reach their maximum level of function and independence in all aspects of life. The activities are selected after being related by the occupational therapist to the individual's personal, social, cultural and economic needs and will reflect the environmental factors which govern his or her lifestyle.

Plan of care

A plan that is based on your individual needs for care.

Physiotherapy

Physiotherapy is concerned with human function and movement and maximising potential. It uses physical approaches (for example, electricity, heat, cold, sound and light), as well as physical activity, exercise and massage to promote, maintain and restore physical, psychological and social wellbeing, taking account of variations in health.

Resuscitation

Restoration of life or consciousness of someone who has collapsed or stopped breathing.

Therapy

The treatment of disorder or disease.

Whistle-blowing

The disclosure by an employee (or professional) of confidential information which relates to some danger, fraud or other illegal or unethical conduct connected with the workplace, be it of the employer or of his fellow employees. (Lord Barrie QC 1995)

Annex B

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Annex B

Useful reference material

Legal

The Adults with Incapacity (Scotland) Act 2000

Under this 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; and
- achieve the desired purpose without unduly limiting the person's freedom.

The Children (Scotland) Act 1995

The Act puts children first. Each child has the right to:

- be treated as an individual;
- form and express views on matters affecting her or him; and
- be protected from all forms of abuse, neglect or exploitation.

Parents and local authorities have rights and responsibilities in achieving the balance of care.

The Data Protection Act 1998

The Act covers how information about living, identifiable people is used and access to their records. All organisations that hold or process personal data must comply.

The Disability Discrimination Act 1995

This wide-ranging Act, which came into force in 1996, makes it illegal to discriminate against disabled people in employment, access to goods, services, transport and education.

The Health and Safety at Work etc Act 1974

The Act is the basic piece of health and safety law that covers everyone who is affected by work activity. It places the burden of legal responsibility for health and safety at work with the employer.

The Human Rights Act 2000

The Act incorporates the European Convention on Human Rights into Scots and English law in relation to the acts of public bodies. Its purpose is to protect human rights and to maintain and promote the ideals and values of a democratic society. The Articles of Convention include:

- freedom of thought, conscience and religion;
- freedom of expression;
- freedom of assembly and association;
- the right to have respect for private and family life; and
- the right to marry.

The Mental Health (Scotland) Act 1984

Currently under review, the Act provides for the compulsory detention and treatment of people with a mental disorder.

The Misuse of Drugs Act 1971

The Act is the main law for drugs control in the UK. It prohibits the possession, supply and manufacture of medicinal and other products except where these have been made legal by the Misuse of Drugs Regulations 1985. The legislation is concerned with controlled drugs and puts these into five separate schedules. Anyone who is responsible for storing or administering controlled drugs should be aware of the content of the Misuse of Drugs Regulations 1985 and the Misuse of Drugs (Safe Custody) Regulations 1973.

The Police Act 1997

Part V of the Police Act 1997 was implemented in April 2002. This provides for the Scottish Criminal Record Office to issue criminal record information certificates to individuals and organisations.

The Public Interest Disclosure Act 1998

The Act protects workers who 'blow the whistle' about wrongdoing. It mainly takes the form of amendments to the Employment Rights Act 1996, and makes provision about the kinds of disclosures which may be protected; the circumstances in which such disclosures are protected; and the persons who may be protected.

The Race Relations Act 1976

The Act makes racial discrimination illegal in employment, service delivery, training and other areas.

The Race Relations (Amendment) Act 2000

The Act makes racial discrimination illegal in public activities that were not previously covered. It puts a general duty on public organisations to promote race equality.

The Regulation of Care (Scotland) Act 2001

The Act establishes a new system of care service regulation including the registration and inspection of care services which takes account of national care standards. The Act also creates two new national, independent bodies, the Scottish Commission for the Regulation of Care, 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.

You can visit these websites for information:

- Regulation of Care (Scotland) Act 2001
www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2001/20010008.htm
- Regulation of Care (Scotland) Act 2001 Statutory Instruments
www.scotland-legislation.hmso.gov.uk/legislation/scotland/s-200201.htm

The Rehabilitation of Offenders Act 1974

The Act enables some criminal convictions to become ‘spent’ or ignored, after a rehabilitation period. The rehabilitation period is a set length of time from the date of conviction.

The Sex Discrimination Act 1975

The Sex Discrimination Act 1975 makes it unlawful to discriminate on grounds of sex or marital status in recruitment, promotion and training. The Act also covers education, the provision of housing, goods and services and advertising.

Policy

Aiming for Excellence: Modernising Social Work Services in Scotland 1999

The White Paper sets out the proposals to strengthen the protection of children and vulnerable adults and to make sure high quality services are provided. The Scottish Commission for the Regulation of Care is an independent regulator set up for this purpose.

Our National Health 2000

The health plan aims to improve Scotland’s health and close the health gap between rich and poor, restoring the NHS as a national service and improving care and standards.

The UN Convention on the Rights of the Child

The Convention is not a law but a code that the Government signed up to in 1991. It recognises that young people under 18 in Scotland do have rights. These rights must be given fairly, and children and young people must be kept safe and well, and able to take part in society.

Other useful references

Administration of medicines

UKCC (2000) Guidelines for the administration of medicines. United Kingdom Central Council for Nursing, Midwifery and Health Visiting.

UKCC (2001) Position statement on the covert administration of medicines. United Kingdom Central Council for Nursing, Midwifery and Health Visiting.

Royal Pharmaceutical Society of Great Britain (2001) The Administration and Control of Medicines in Care Homes.

Guidelines for Safe and Secure Handling of Medicines – A report to the Secretary of State for Social Services. RB Duthie 1988. Gen 33.

Control of Substances Hazardous to Health (COSHH) Regulations 1988.

The Right Medicine: A Strategy for Pharmaceutical Care in Scotland 2002.

CSBS Standards Ovarian Cancer, Colorectal Cancer, Breast Cancer, Lung Cancer 2001.

Palliative care

Control of Pain in Patients with Cancer. SIGN 44 2000.

Specialist Palliative Care Standards. Clinical Standards Board for Scotland 2002.

Guidelines for Good Practice in a Children's Hospice. Association of Children's Hospices 2001.

Fulfilling Lives: Rehabilitation in Palliative Care. National Council for Hospice and Specialist Palliative Care Services 2000.

Cancer in Scotland: Action for Change. Scottish Executive 2001.

A Guide to the Development of Childcare Palliative Care Service. ACT, RCPCH 1997.

Relief of Pain and Related Symptoms: The Role of Drug Therapy, 3rd edition, August 2000. Dr Barbara Dymock and Angus MacConnachie for the Scottish Partnership Agency for Palliative and Cancer Care.

Scottish Partnership for Palliative Care

Information about palliative care in Scotland, including details of voluntary hospices and NHS services, is available on the website of the Scottish Partnership for Palliative Care at <http://www.palliativecarescotland.org.uk>

The Partnership is the co-ordinating and representative body for palliative care in Scotland and its website also provides useful links to other organisations, publications and sources of information.

Infection control

Thomlinson D. Time to Dispense with the Rituals. Professional Nurse 1990; 5(8): 421-425.

Grazier S. The Loneliness Barrier. Nursing Times 1988; 84(41): 44-45.

Advisory Group on Infection. Scottish Infection Manual: Scottish Office Department of Health, 1998.

Clinical Governance Making it Happen, 3rd edition. Lugon M. S-WJE. The Royal Society of Medicine Press Limited, 1999.

Healthcare Associated Infection (HAI) Control Standards. Clinical Standards Board for Scotland, December 2001.

Risk management

Clinical Negligence and Other Risks Indemnity Scheme (CNORIS) Healthcare Risk Management Standards.

Volunteers

NHS MEL (2000)04 Volunteering in the NHS in Scotland.

Miscellaneous

Seeking Patients' Consent: The Ethical Considerations. General Medical Council 1998.

Confidentiality: Protecting and Providing Information. General Medical Council September 2000.

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